WELLNESS WITHIN ILLNESS AND THE CAPACITY FOR HAPPINESS IN PEOPLE WITH ALZHEIMER'S DISEASE: USING PHOTO-ELICITATION METHOD TO COMPARE THE PERSPECTIVES OF PEOPLE WITH ALZHEIMER'S DISEASE AND THEIR CAREGIVERS

by

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ABSTRACT

Quality of life for people with dementia is a topic of great concern and study, due in part to the growing number of people diagnosed with Alzheimer's disease and other dementias. Happiness is an important aspect of well-being and quality of life, yet the subjective experience of happiness in dementia has not been explored. The purpose of this study was to examine the subjective experience of happiness for persons with mild to moderate Alzheimer's disease from the perspective of the person living with the disease and their caregiver through the use of photo-elicitation with autodriving methodology.

A sample of 12 persons with mild to moderate Alzheimer's disease were given cameras and asked to take photographs representing happiness. The 12 caregivers were invited to participate in the study; 10 agreed. Caregivers were given cameras and asked to take photographs representing happiness for their care recipient partner. The photographs served as the basis for one-on-one interviews between the participant and the researcher.

In this study, persons with Alzheimer's disease identified long-held values as important to their happiness, including connection to others, nature, transcendence, preservation of self, and joyful moments. Individual differences and nuanced interpretations were noted within each identified value. Many of the same images were taken by the caregivers. However, study results point to the caregiver's general lack of awareness and understanding of the presence and role of values.

The implications of this work are significant in that they help to advance our understanding of happiness in Alzheimer's disease and propel us forward toward the development of measures and interventions supportive of quality of life in this

population. Additionally, the findings of this study further our understanding of the inter-subjective relationship of the person with Alzheimer's disease and the caregiver, underscoring the need to support both members of the dyad through person-and family-centered care to improve quality of life and maintain the personhood of both the person with Alzheimer's disease and the caregiver. Finally, this study broadens our understanding of Alzheimer's disease from the current paradigm of despair and loss to one that includes the possibility of happiness and well-being.

This dissertation is dedicated to my mom, Lorraine Fugazzi Pebole . . .

for everything.

TABLE OF CONTENTS

ABSTRACT iii

ACKNOWLEDGMENTS ix

CHAPTERS

1 INTRODUCTION 1

Statement of the Problem 1
Medical Model of Alzheimer's Disease 2
Failure of Quality-of-Life Measures to Account for Subjective Well-Being 3
Theoretical Framework 4
Purpose and Significance 6
Research Questions 7
Specific Aims 8
Organization of Study Findings 8
References 9

2 BACKGROUND AND SIGNIFICANCE 11

Review of the Literature 11
Historical Understanding of Alzheimer's Disease 12
The Biomedical Model of Dementia 14
Prevailing Theories of Happiness and Well-Being 20
Looking for Happiness: Previous Research on Happiness in Dementia 23
Role of Emotional Well-Being in Physical Health 24
Measures of Well-Being in Quality-of-Life Tools 28
The Challenge of Retrospective Life Review: Two Perspectives on One Life 33
Conclusion 36
References 37

3 THEORETICAL AND METHODOLOGICAL FRAMEWORK 43

Introduction 43
Social Constructionism and Symbolic Interactionism 43
Kitwood's Psychosocial Model of AD 44
Positive Psychology 47
Comparison of Biomedical Model, Kitwood's Theory of Personhood, and Positive Psychology 50

Wellness within Illness 52
Assumptions in My Study of Wellness within Illness in AD 54
Methodological Framework 60
Study Design 64
Method of Data Collection 66
Methods of Data Analysis 68
Human Subjects Consideration 71
References 73

4 PHOTO-ELICITATION AS A RESEARCH TOOL WITH PERSONS WITH ALZHEIMER'S DISEASE: ETHICAL DILEMMAS AND LESSONS LEARNED 79

Abstract 79
Introduction 80
Photo-Elicitation 82
Context of Current Research 84
Research Design 86
Data Analysis 90
Methodological Challenges 91
Using Photo-Elicitation and Autodriving Techniques with Persons with Alzheimer's Disease: Lessons Learned 99
Advantages of Photo-Elicitation and Autodriving Techniques with Persons with Alzheimer's Disease 101
Conclusion 102
References 103

5 WELLNESS WITHIN ILLNESS: HAPPINESS IN PERSONS DIAGNOSED WITH ALZHEIMER'S DISEASE 107

Abstract 107
Introduction 108
Study Purpose 110
Impact of Alzheimer's Disease 111
Correlates of Well-Being: Connecting Well-Being to Mental and Physical Health 112
Methodology 113
Data Analysis 119
Findings 120
Discussion 135
Study Limitations 142
Future Studies 142
Conclusion 143
References 145

6 HAPPINESS IN PERSONS DIAGNOSED WITH ALZHEIMER'S DISEASE: THE PERSPECTIVE OF THE CAREGIVER 150

Abstract 150
Introduction 151
Context of Current Research 152
Personhood 153
Subjective Assessment of Quality of Life by Proxy and Person with Alzheimer's Disease 154
Study Purpose 156
Methodology 157
Data Analysis 163
General Observations of the Study Participants 164
Findings 166
Discussion 176
Future Studies 181
Study Limitations 182
Conclusions 182
References 184

7 CONCLUSION 188

Happiness from the Perspective of the Person with Alzheimer's Disease 188
Happiness for the Person with Alzheimer's Disease from the Perspective of the Caregiver 190
Intersubjective Experience of Alzheimer's Disease 190
Limitations 190
Recommendations 191
Final Thoughts 197
References 199

APPENDIX:

COMPARISON OF BIOMEDICAL, KITWOOD'S THEORY OF PERSONHOOD, AND POSITIVE PSYCHOLOGY 200

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CHAPTER 1

INTRODUCTION

Statement of the Problem

As a geriatric mental health nurse practitioner, I speak with older clients struggling to adjust to physical and cognitive changes. The experience of Mrs. K. is typical of many elders. At age 75, she became depressed as she realized that her diminished memory and cognition lessened her ability to function independently. She feared becoming a "burden" and perceived her future as "worse than death." Clients like Mrs. K. generated my interest in understanding the experience of Alzheimer's disease.

The worldwide estimate of people living with Alzheimer's disease (AD) in 2010 is 35.5 million. This number is expected to grow to 65.7 million by 2030 (Alzheimer's Disease International, 2012). Add to this the number of caregivers and family members who are also affected by the disease, and the number of people directly and indirectly impacted by AD is staggering. Each individual living with AD confronts uncertainties about future health and prognosis (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). To date, no prevention or cure for AD has been developed. While the disturbances in cognition and behavior that significantly limit an individual's ability to function independently are present in severe dementia, mild AD can also cause problems. The individual may struggle with memory loss while still being able to communicate and participate meaningfully in a social context; he or she may also still be able to performsome personal care and daily living activities (Cahill et al., 2004).

In AD—as in other diseases without a cure—the improvement of quality of life associated with maintaining optimal physical and emotional health is an important goal in an effort to reduce disability and suffering. Early diagnosis and pharmacological interventions to slow the progression of AD now exist that were not available prior to donepezil's approval for use in mild to moderate AD in 1996. There is now sufficient time for interventions to improve quality of life in persons with mild to moderate AD.

Although quality of life has become a major topic in AD research, it is not always clear what this term means or how it is conceptualized. This confusion is evident in the development of quality of life assessment tools that utilize inconsistent constructs, thereby making comparison of research results difficult, if not impossible. Variability exists in the method of response (self-report vs. proxy); terms such as well-being, positive affect, and happiness are used interchangeably and without clear definitions; and choice of foundational constructs measured. In addition, while most quality of life measures include a component of positive affect, most often treated as a sign that is read by others rather than a subjective measure, it is the researcher who chooses the domains to be assessed. Hence, the perspective of the person with AD is frequently overlooked, leaving one to wonder if conventional quality of life and outcome measures are significant, or even relevant, to the population being assessed.

Medical Model of Alzheimer's Disease

The majority of the information currently available about mild to moderate AD is derived from, and limited by, research based on the medical model, which is focused on pathology, dysfunction, and the physical and biologic aspects of disease (Lyman, 1989). As a result, there is no understanding of AD that is compatible with healthy aging and

therefore no possibility of conceptualizing *wellness within illness* in this population. In social discourse and medical literature, *dementia* and *positive aging* (a concept that includes happiness) are concepts that rarely intersect and are generally viewed as mutually exclusive. However, from the perspective of the science of positive psychology that aims to build on strengths rather than focus on loss, these concepts can occur simultaneously. Efforts have been made to measure quality of life, including happiness and its analogs, in persons with AD. However, there is currently no understanding of the subjective experience of happiness in this population.

I recognize a need to move beyond the medical model of AD, which is limited to a unidimensional, pathologized view, toward one including positive emotions such as happiness and well-being—a concept of quality of life that does not see the symptoms of AD and a subjective sense of well-being as mutually exclusive possibilities. Currently there is no research on the subjective experience of happiness in persons with mild to moderate AD and no information on factors supporting happiness and well-being in this population.

Failure of Quality-of-Life Measures to Account for Subjective Well-Being

Without a clear definition of quality of life, developing tools to measure the construct is difficult, if not impossible. Most quality of life measures include a component of positive affect, an important variable to consider as current research suggests a connection between positive emotion, happiness, and well-being to benefits in many aspects of physical health, including decrease in cortisol levels, improvement in rates of depression remission, protection against coronary heart disease, and increasing

social engagement and cognitive stimulation (Ryff, Singer, & Love, 2004; Steptoe, Wardle, & Marmot, 2005). However, it remains unclear whether affect as conventionally defined and operationalized in such studies adequately represents the constructs of happiness or subjective well-being, thus presenting a major challenge to construct validity of quality of life tools.

Little research to date has focused solely on the subjective or emic experience of happiness. Despite recent research suggesting that persons with AD can meaningfully comment on their quality of life, much of the current understanding of positive affect in AD comes from quality of life studies in which information was obtained from proxy caregivers (Logsdon, Gibbons, McCurry, & Teri, 2002; Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996). The use of proxy reports highlights one of several underlying assumptions of quality of life tools—namely, that it is possible to observe and evaluate the happiness in others, which challenges the construct validity of the tool. Moreover, the quality of life assessment methodology of evaluating domain scores assumes that quality of life can be understood as the sum of those scores, in which being contented in one domain can compensate for a low score in another domain, which is a broad oversimplification. Finally, it is difficult to imagine that a construct for which there is no apparent definition or even conceptual agreement can be reflected clearly in a measurement tool.

Theoretical Framework

My theoretical orientation—which includes concepts from constructionism, symbolic interactionism, positive psychology, and Kitwood's theory of personhood—is explained

in the next section to help the reader understand the framework that will be used in this study.

Constructionism and Symbolic Interactionism

According to constructionism, meaning is derived from our engagement with the world, reflecting the understanding of the experiences of the individual (Crotty, 1998). The constructionist view will inform the symbolic interactionist approach, which assumes that people assign meaning to their circumstances and that these meanings result from interaction with others (Schwandt, 2001). Symbolic interaction presumes humans exist in a world of objects, the nature of which is determined by the meaning the object has for the individual (Blumer, 1966). Both constructionism and symbolic interactionism stress the importance of subjective meaning in the study of human behavior.

Symbolic interaction serves as my grand theory, supplying a specific set of assumptions upon which this research is based. Positive psychology and Kitwood's theory of personhood function as the midrange theory, providing a framework that informs my research question and aims and the lens through which I interpret the utility and implications of the findings.

Positive Psychology

The term *positive psychology* was used by Abraham Maslow in 1954 and later reintroduced by Martin Seligman in 1999 to note the imbalance of psychology's focus on illness as compared to strengths and potentialities (Lopez & Gallagher, 2009). The goal of positive psychology is to add positive processes such as resilience, strength, and growth to the existing knowledge of pathology and dysfunction and to use this knowledge to develop interventions that support these positive processes (Gable & Haidt,

2005). In Seligman's extensive work in this field, he identifies primary factors that influence one's level of happiness, including intentional voluntary activity that may provide the best route to increasing happiness (Seligman, 2002).

Tom Kitwood's Theory of Personhood

Kitwood (1997) defined *personhood* as "a standing or status that is bestowed upon one human being by others" (p. 8). Kitwood believed personhood is essential to ensure the humanity of the person with AD. Challenging the biomedical paradigm of AD focused on pathology, decline, and loss, Kitwood viewed all losses and difficulties in later life, including AD, as socially constructed. According to Kitwood, personhood may be undermined by social factors or supported by positive exchanges with others. Kitwood assumed that a person diagnosed with AD can experience well-being if his needs are met and the level of human interaction is high (1990). In this study, supported by the underpinnings of constructionism and symbolic interactionism, photographs and the interviews describing their meaning served as the symbolic representations to be analyzed to gain access to the individual's interpretation of happiness.

Purpose and Significance

The purpose of this study is to explore the subjective experience of happiness in persons with mild to moderate AD from the perspective of the science of positive psychology, building on strengths rather than focusing on loss. Looking at AD through the lens of positive psychology allows for the possibility to change the narrative from one of loss to one that includes adaptation, strength, and happiness (Seligman & Csikszentmihalyi, 2000). I aim to develop a new level of understanding of AD, ensuring that decisions related to treatment and end of life choices are made with an appreciation

of the full experience of AD. This will be the first step toward the development of a theory of happiness as well as interventions to increase happiness, increase well-being, and improve the quality of life in this population across multiple contexts.

In the face of the worldwide dementia epidemic, some might argue that the study of positive emotion in AD is a luxury that we cannot afford, and that effort should instead be directed to prevention and cure of AD. I believe that there are a number of compelling reasons why the study of happiness is valuable. First is the cause of compassion. Clear understanding of the experience of happiness in AD may allow for the development of interventions to lessen emotional pain and suffering and improve quality of life. Second, current research suggests a connection between positive emotion and physical health, suggesting the potential to reduce healthcare costs. Third, only by understanding the full experience of AD—including the opportunity for strength, resilience, happiness, and well-being—can we challenge the current paradigm of AD, which fosters stigma, creates isolation, and induces fear.

Research Questions

Previous research has explored happiness and well-being in the context of dementia care using limited constructs determined by the researcher or caregiver rather than from the subjective experience of the person with dementia, leaving findings open to the possibility of researcher bias and challenges to concept validity.

In this qualitative, interpretive study, the concept of happiness in the context of mild to moderate Alzheimer's disease will be explored from the subjective (emic) perspective utilizing photographs as a means of communication between the researcher and the participant.

Specific Aims

The specific interrelated aims of this study are:

—Aim 1: To describe the subjective understanding and perception of happiness in individuals with mild to moderate AD.

—Aim 2: Compare and contrast what people with AD consider important to their happiness to what the caregiver believes is important for their happiness.

Organization of Study Findings

The study findings are reported in manuscript format in the following chapters:

—Chapter 4, "Photo-Elicitation as a Research Tool with Persons with Alzheimer's Disease: Ethical Dilemmas and Lessons Learned," reports the usefulness of photo-elicitation as a research methodology in persons with AD.

—Chapter 5, "Wellness within Illness: Happiness in Persons Diagnosed with Alzheimer's Disease," reports the results of testing Aim #1.

—Chapter 6, "Happiness in Persons Diagnosed with Alzheimer's Disease: The Perspective of the Caregiver," reports the results of testing Aim #2.

—Chapter 7 summarizes the findings for each specific aim and reports the study conclusions.

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CHAPTER 2

BACKGROUND AND SIGNIFICANCE

Review of the Literature

An historical overview of the development of the concept of Alzheimer's disease (AD) shows how rooted in medical discourse the concept is and how subsequent developments, measures, and interventions based on this medical disease model reproduce assumptions that limit how we perceive people diagnosed with AD, especially in terms of emotional capacity. In the following sections I provide an historical perspective of dementia, including both its roots in the biomedical model and challenges to that model. I then review theories of happiness and the role happiness and positive emotion play on physical health and quality of life. I conclude with a discussion of the dilemma associated with the use of a retrospective subjective life review as an assessment tool. This review of the literature suggests that my study is very much needed because of the limited understanding of how people with AD experience happiness.

Elucidating the views of the people living with AD may help to challenge the current negative assumptions associated with the disease and aid in the development of a more realistic view of life with AD. It may also provide insight important for the development of interventions to support positive emotion and thus improve quality of life for those with AD.

Historical Understanding of Alzheimer's Disease

The first published description of dementia appeared in 1907 by Dr. Alois Alzheimer. He reported findings of plaques and tangles obtained during the autopsy of Frau Auguste Deter, a female patient at the Frankfurt Mental Institution in Frankfurt, Germany who presented with memory loss, delusions, and behavioral disturbance (Ballenger, 2006). Dr. Emil Kraepelin, who believed the chief cause of psychiatric disease to be biological and genetic defect, included Dr. Alzheimer's findings in his textbook of psychiatry, coining the term *Alzheimer's disease* (Fotuhi, Hachinski, & Whitehouse, 2009). However, references to age-related cognitive impairment actually appear much earlier, starting with the Greek physician Pythagoras in the 7th century BCE (Berchtold & Cotman, 1998).

Berchtold and Cotman's (1998) historical overview of the emergence of concepts of dementia highlight the medicalization of the disease. Pythagoras divided the life cycle into five distinct stages beginning at ages 7, 21, 49, 63, and 81; he identified the last two stages as a period of cognitive deterioration. Plato and Aristotle later supported the belief that cognitive decline was an expected part of aging. In the 2nd century BC, Roman philosopher Cicero challenged the belief that cognitive decline was inevitable in old age, suggesting that by remaining mentally active, one might prevent or delay the progression of decline. Cicero's opinion was overshadowed by the work of Aristotle and largely ignored.

In the writings of Roman physician Galen (150–200 CE), *morosis* (the word he chose for dementia) was listed as a mental disorder that occurred in old age. Dementia was not viewed as a natural process but as "an inevitable infection of the body" (Berchtold & Cotman, 1998, p. 175). According to Berchtold and Cotman (1998), it is

likely that equating old age with an inevitably demented state by the Greco-Romans laid the foundation for the changing definition of the term *senile* from its original sense denoting "advanced age" to its later usage denoting "demented" (p. 175). Little change occurred in the understanding of dementia until the 18th century, when the concept of dementia was refined and *senile dementia* was recognized as a medical condition distinct from normal aging (Berchtold & Cotman, 1998).

In the 19th century, the concept of senile dementia was more narrowly defined and differentiated from other medical conditions. Anatomists examined the brain on autopsy for structural alterations and noted changes in weight associated with atrophy and cell death. Simultaneous improvement in microscopes led to the discovery of pathological features, including plaques. The work of Dr. Alzheimer and Dr. Otto Binswanger emphasized the concept of chronic cerebral ischemia and arteriosclerotic brain atrophy in the late 1890s (Fotuhi et al., 2009; Mast, Tatemichi, & Mohr, 1995). In 1907, Alzheimer published his autopsy findings of plaques and tangles found in Frau Deter, which was later reported by Dr. Kraeplin as AD (Fotuhi et al., 2009).

While the medical understanding of AD was developing, so was the fear associated with the disease. Ballenger (2006) argued that the fear and anxiety associated with AD today emerged in the American culture in the late 18th century. In a pamphlet on old age written by Dr. Benjamin Rush in 1793, Rush described the loss of memory and other degenerative physical changes that continue to be concerns associated with AD. Placing the pamphlet in its historical context, Ballenger argued that social and medical discourse surrounding aging and dementia was "primarily concerned with the relationships that the aged individual maintained with God and the community of faithful" (p. 4) and placed the clergy as the authority on aging. As a result, dementia was

linked to the idea of one's ultimate dependence on God and was associated with less fear and anxiety than today. During this time, perceptions of old age were deeply rooted in religion, and its challenges were understood as part of the harmony and balance of God's grace. As such, even those with dementia had a place in the community, and Americans were relatively tolerant of the aged. Ballenger (2006) noted that by the 1820s, the ideas of a preordained fate and a God with absolute sovereignty were replaced with ideas of a benevolent God and the individual's responsibility to lead a virtuous life to obtain rewards from God. In this way, suffering was the result of moral, personal failure. Ballenger noted that it was at this time that physicians replaced clergy as the authority on aging. The biomedical model, which views AD in terms of cognitive and functional decline, has remained dominant in Western cultures through most of the 20th century (Downs, 1997).

The Biomedical Model of Dementia

The dominant disease model currently in use in the United States is the biomedical model, developed by medical scientists for the study of disease. Grounded in molecular biology, the biomedical model of disease is a scientific model and is based on the scientific method with a shared set of assumptions (Engel, 1977). The model assumes disease to be founded in biochemical processes and "fully accounted for by deviations from the norm of measurable biological (somatic) variables" without consideration for the social, psychological, and behavioral dimensions of the illness (Engel, 1977, p. 130).

Embedded in the biomedical model is reductionism, which suggests that (1) all symptoms and signs emanate from an underlying abnormality in the body, (2) that health is the absence of disease, (3) that biological phenomena can be explained by laws of

chemistry and physics, and (4) that a mind-body dualism exists that is the separation of mental phenomena from physical disturbance (Engel, 1977; Wade & Halligan, 2004). Within this understanding, neurodegenerative changes in the brain produce progressive cognitive decline, resulting in impairment to memory, reasoning, and decision-making capacity. According to the biomedical model, these changes eventually lead to loss of personhood and death and require treatment from the medical profession (Bond, 1992).

Social Understanding of Dementia Drawn from the Biomedical Model

Dominant social understandings of dementia reflect and reproduce the medical deficit-based model. The *Merriam-Webster Online Dictionary* defines dementia first as "a usually progressive condition (as AD) marked by deteriorated cognitive functioning often with emotional apathy" and second as "madness, insanity" identifying "insanity, derangement, lunacy" as synonyms (retrieved September, 2010). These pejorative terms both inform and reflect the cultural understanding of the disease, shaping the public consciousness of dementia. The struggle of people with dementia to adapt to their diagnosis and the associated losses while retaining a sense of purpose and meaning is hindered in part by this social perception of the disease.

Several studies have reported that many elderly people perceive living with AD as a state of severe suffering due to increased dependence on others and the progressive loss of autonomy and identity (de Boer et al., 2007; Laforce & McLean, 2005). Nursing students described feeling afraid, sad, and nervous when caring for persons with dementia (Beck, 1996). Henderson and Gutierrez-Mayka (1992) found that some Hispanics viewed elders with dementia as being "crazy" or having "bad blood," a stigma that may be placed

on the entire family as well. Such cultural implications among caregivers help create barriers to seeking assistance outside the family. Touhy (2004) noted that descriptions of AD bring up "images of mute people sitting in wheelchairs condemned to a life of nothingness" (p. 43). It is this shared public belief of AD that serves as the backdrop to the conversation patients have with their healthcare provider, family, and friends, resulting in fear and stigma.

Challenges to the Biomedical Disease Model

The biomedical model is not the only model of disease. Culturally derived belief systems also exist. These may include not just the disease associated phenomena to which all social groups will be exposed, but also explanations, rules of behavior for treatment, and social adaption specific to that culture. These folk models are not based on the scientific model. Engel (1977) suggested that in Western society, the biomedical model has also become the dominant folk model of disease and has taken on the status of *dogma*, which "requires that discrepant data be forced to fit the model or be excluded" (p. 130).

While the biomedical model is associated with advancement in medical care, it traditionally focuses on discovering pathology rather than understanding the disease (Wade & Halligan, 2004). According to the biomedical model, AD must therefore be conceptualized in terms of biochemical principles that exclude psychosocial variables, such as positive emotion that may either contribute to or limit illness and illness behavior. In the biomedical model, the person with AD becomes positioned as a patient and emphasis is placed on the burden experienced by caregivers.

Research on AD "caregiver strain" framed by the biomedical model attributes problem behaviors to disease progression, neglects social and psychological factors, and shifts attention away from the person with AD and toward the burden of the caregiver (Harris, 2002; Lyman, 1989). Herskovits (1995) suggests the images of the person with AD as *bizarre* and *a shell of his former self* are contrary to accepted cultural norms and values, minimizing the individual's status of human. "As a result, people with dementia are largely invisible in most of this literature; they are merely disease entities, independent variables" (Lyman, 1989, p. 603).

Lyman (1989) notes that the narrow biomedical view of disease minimizes the importance of social factors that can affect the progression and expression of dementia. Lyman suggests a broader vision of AD, one that includes the cultural definition and the socioenvironmental context of care. Utilizing the biomedical view of AD, Lyman (1989) identifies and then refutes its three predominant features. First, AD is an abnormal pathological condition of cognitive impairment and dysfunction. Lyman challenges the idea of AD as a pathological condition by asking what is normal and what comprises a behavioral quirk. The impact of labeling an individual "abnormal" and treating him or her as if he or she were demented may result in limiting social opportunities, creating social isolation and stigmatization, threatening independence and maintenance of valued roles, and significantly worsening the impact of AD. Holding on to one's former self is especially difficult when others impose an illness identity on the person (Charmaz, 1990).

A second feature of AD as viewed through the biomedical model suggests that AD is caused by progressive deterioration of the brain, affecting intellectual functioning and resulting in stages of progressive severity. Lyman counters this view by pointing to the limited epidemiologic and medical knowledge about the causes of AD and the

evidence from longitudinal studies that contradict the universality of stages of progressive brain deterioration. Lyman points out that although some in the medical community acknowledge the variability in the course of AD, the reference to three stages of AD—mild, moderate, and severe—continue to be identified in the literature.

The third feature of AD challenged by Lyman is that it can be diagnosed by biomedical assessment of brain disease and clinical functioning and that it can be treated medically. According to Lyman (1989), Alzheimer's-type brain lesions are found on autopsy in individuals with normal intellectual function. Lyman also argues that clinical functioning can be misinterpreted, with dependency being encouraged and independence discouraged in long-term care facilities and by some family caregivers due to the stress associated with caregiver burden.

In summarizing the biomedical paradigm of AD, Lyman labeled it "nearsighted" for its limited focus on only those aspects of AD that can be explained by brain disease. Cantley and Bowes (2004) suggest the biomedical model can lead to the institutionalization and exclusion of people with AD.

Advances in the diagnosis of AD have occurred since Lyman's article was written in 1989, a time when clinicians understood definitive diagnosis to be possible only on autopsy. Since then, biomarkers of AD have been identified that can be measured in vivo and indicate disease-related pathological change. Jack et al. (2010) identify the five most widely used biomarkers of AD as: decreased beta-amyloid peptides $A\beta_{1-42}$ in the cerebrospinal fluid (CSF); increased CSF tau, suggesting neuronal injury, which, though not specific for AD, is associated with disease severity and neurofibrillary tangles (NFTs); decreased fluorodeoxyglucose uptake on positron emission tomography (PET), a nuclear medicine imaging technique that indicates reduced brain metabolism and

impaired synaptic function; PET imaging of Aβ plaque deposits in the brain; and magnetic resonance imaging (MRI) measures of brain atrophy. Structural MRI is used in the clinical assessment of patients with both AD and other dementias. Rates of brain and hippocampal atrophy measurable on MRI can be used as outcome measures in interventional trials (Frisoni, Fox, Jack, Scheltens, & Thompson, 2010). The identification of biomarkers allows greater specificity of AD diagnosis, differentiating AD from other dementias and nondementia causes, such as depression. The increased precision in AD diagnosis minimizes some of the variability in course of AD identified by Lyman previously due to inclusion of different illnesses (Dubois et al., 2007).

While the epidemiological and biochemical knowledge of AD has increased, Lyman's comments are still relevant. Evidence suggests that AD is an evolving process starting years before the onset of clinical symptoms that follows a predictable pattern of progression in the brain, which can be staged (DuBois et al., 2007). Jack et al. (2010) identify three different clinical phases of AD based on symptom expression rather than presumed acuity. In the first phase, presymptomatic AD, the individual is "cognitively normal but some have AD pathological changes" (p. 120). The second phase is a prodromal phase of AD frequently referred to as mild cognitive impairment in which the person experiences some cognitive symptoms that do not meet the criteria for AD. The final phase is AD, with significant impairments resulting in loss of independence. Jack et al. (2010) point out that progression through the phases can be affected by several factors, including comorbidities and enhanced cognitive reserve, supporting Lyman's questioning of the universality of progression. Specific AD biomarkers have been proposed for staging of AD in vivo, but as of yet those biomarkers are not in place.

Prevailing Theories of Happiness and Well-Being

One challenge to the study of the capacity to experience and express happiness and well-being in people with AD is the wide variety of terms used as descriptors. The terms *well-being*, *life satisfaction*, *positive affect*, and *happiness* are frequently used interchangeably, referring to a positive attitude toward life. George (2010) reports the key difference among the terms is stability—with happiness being less stable and less cognitive than life satisfaction, and positive affect the least stable, changing rapidly to stimuli in the immediate environment. George concluded, however, that these terms are more similar than different, essentially all measuring "subjective perceptions that life as a whole is good" (p. 332), citing findings from confirmatory factor analysis studies that indicate measures of life satisfaction, happiness, and positive affect all loading on a single dimension.

As Hill (2011) exemplifies in the concept of positive aging, happiness and well-being have been, and continue to be, the focus of a significant number of sociological and psychological studies of aging. As a result, several theoretical orientations have been developed and used in research. I will review some of the key theories and findings here in order to illustrate the social and contextual factors that influence happiness as well as the role cognition plays in our current understanding of positive emotion.

Discrepancy Theories

Subjective well-being is based on a balance of aspirations and attainment, with well-being and happiness highest when the discrepancy between desires/hopes and achievement is small. On average, the elderly report lower discrepancy between desires and achievement than other age groups (George, 2010). Cheng (2004) found that when

compared to younger groups, older adults identified smaller discrepancies in material resources and social relationships but larger health discrepancies. The older adults in this study reported higher levels of subjective well-being than the middle-aged and younger adults.

Hedonism

Hedonism is an ancient Greek tradition based in the ideas of pleasure, happiness, and the satisfaction of human desires. Greek philosopher Aristippus and followers Hobbes and DeSade taught that the goal of life was to experience the maximum amount of happiness (Ryan & Deci, 2001). Hedonism is currently more broadly defined to include subjective judgments of the good and bad elements of life that reflect an individual's values and the ability to reach those values and goals, not just the obtainment of pleasure (Diener, Sapyta, & Suh, 1998). Unlike the eudaimonic approach to happiness, which focuses on meaning and self-realization and defines well-being in terms of the degree to which a person is fully functioning, the hedonic approach focuses on happiness and defines well-being in terms of pleasure attainment and pain avoidance (Ryan & Deci, 2001).

Social Comparisons

In this theory, subjective well-being is determined by the group against which we measure ourselves and to which we compare our own accomplishments. If we compare ourselves to others who are more advantaged, our subjective well-being is lower than if we compare ourselves to others who are less advantaged. George (2010) reported that older adults are more likely than younger adults to compare themselves to those less fortunate. In Beaumont and Kenealy's (2004) study of 190 healthy elders age 65 or older

(mean age 77), 78% of the participants reported comparing themselves to individuals believed to have a lower quality of life. Referred to as *downward contrast*, this strategy was associated with a higher perceived quality of life, although whether this reflects a cohort effect or an age effect is unclear.

These theories are important to note because they advance our level of understanding beyond the individual and/or intrapersonal, allowing us to consider the way in which social factors and context complicate more simplistic models. However, they are still too reductionist, objective, and narrow to effectively operationalize wellness within illness or the understanding of a more emic, subjective sense of happiness for persons diagnosed with AD.

Much of the recent research on happiness comes from the work of Martin Seligman. Seligman developed a conceptual framework for authentic happiness that divided the concept of happiness into three components: positive emotion and pleasure, which Seligman compares to the hedonic interpretation of happiness (the pleasant life); engagement, the use of character strengths and virtues (the engaged life); and purpose (the meaningful life), which stresses belonging to and serving what is more worthwhile than the just the self's pleasures and desires. Seligman suggests that people differ according to the type of life they pursue and that the most satisfied people are those who pursue all three, with the greatest weight carried by engagement and meaning. Seligman calls a life that satisfies all three criteria of happiness the "full life" (Seligman, 2008; Seligman & Steen, 2005; Slade, 2010).

Enduring happiness (Seligman, 2002), also referred to as *chronic happiness*, refers to a person's characteristic level of happiness, a feeling that is more enduring than momentary or daily happiness but that is also malleable over time. One's enduring

happiness level is more difficult to change than one's happiness level at any particular moment. Operationally, a person's chronic happiness level might be defined by his or her retrospective summary judgments of mood and satisfaction during a recent period (Lyubomirsky, Sheldon, & Schkade, 2005; Seligman, 2002).

Looking for Happiness: Previous Research on Happiness in Dementia

Many quantitative and qualitative studies report on positive affect as measured on various quality of life tools, but few report on the subjective meaning of happiness. However, research has been hampered by attempts to reduce happiness and well-being to a single measure of affect or mood, thereby minimizing the usefulness of research results and calling construct validity into question. With that admonition, I will review qualitative studies of happiness in the context of mild to moderate AD.

In an exploratory study conducted by Droes et al. (2006), including persons with mild to moderate AD living in the community, participants identified happiness and tranquility as being important for quality of life. Cahill et al. (2004) and Katsumo (2005) collected both qualitative and quantitative data in persons with AD to assess quality of life. In both studies, family was identified as a source of happiness for the participants. Cahill et al. (2004) also noted contact with others, keeping active in church, gardening, and the "simple things in life" as sources of happiness (p. 320). Moyle, McAllister, Venturato, and Adams (2007) studied persons in residential care settings in Australia with mild to moderate AD. They report higher quality of life was associated with better interpersonal relationships, thus supporting research indicating the importance of social networks.

Byrne-Davis, Bennett, and Wilcock (2006) describe a *priori* hypotheses that quality of life declines with increasing cognitive impairment (p. 856). The authors analyzed quality of life ratings in 25 community-dwelling persons with mild to severe AD who participated in focus groups using open-ended questions. The authors conclude that happiness may influence perception of important issues, including one's ability to cope, and as such is deserving of subjective assessment as part of quality of life. Finally, Smith et al. (2005) looked at the existing literature and qualitative data to develop a conceptual framework for health-related quality of life. Using in-depth interviews, the authors identified five domains, one of which was health and well-being described in terms of happiness, contentment, and enjoyment of life.

Although the research presented has helped move our understanding of wellness within illness forward by presenting the voice of the person with AD, the usefulness of the results is hindered by the reductionist approach, which prevents the emergence of an understanding of well-being that goes beyond the narrow construct utilized in the study. While the research reviewed offers some additional understanding of positive emotion, the results continue to be inadequate, vulnerable to the challenge of concept validity and offering minimal information regarding the way in which subjective perceptions and experience influence the people's sense of happiness and well-being.

Role of Emotional Well-Being in Physical Health

The core hypothesis of positive health has been identified as the contribution of well-being to the maintenance or restoration of health and physical functioning of an individual (Ryff, Singer, & Love, 2004). Although the measured constructs of positive

emotion vary between studies, sufficient evidence does exist to suggest an association between well-being and physical and psychosocial health.

Multiple studies have suggested an association between positive emotions and improved biological markers. Steptoe, Wardle, and Marmot (2005) reported an inverse relationship between happiness and elevated heart rate, a marker predictive of mortality and cardiovascular disease (as well as reduced neuroendocrine, cardiovascular, and inflammatory activity), while Ostir, Berges, Markides, and Ottenbacher (2006) found positive emotions to be associated with lower systolic and diastolic blood pressure. In a meta-analysis of 35 such studies, Chida and Steptoe (2008) concluded that positive psychological states may influence inflammatory and coagulation factors involved in cardiovascular disease and may lower levels of cortisol, a major stress hormone with a role in several medical illnesses, including Type 2 diabetes, hypertension, and autoimmune diseases. Steptoe (2010) also reported an inverse relationship between positive affect and cortisol levels independent of covariates, including depressed mood, age, gender, socioeconomic status, smoking and body mass.

Positive emotion has also been associated with psychosocial factors such as greater social connectedness, larger social support network, and protective behaviors (Chan & Lee, 2006; Steptoe, Dockray, & Wardle, 2009). Increasing social engagement may lead to cognitive stimulation, which may in turn decrease the risk of AD and improve cognitive abilities (Knapp et al., 2006; Mendes de Leon, Glass, & Berkman, 2003). Holt-Lunstad, Smith, and Layton (2010) conducted a meta-analysis of 148 studies to determine the impact of social relationships on mortality, concluding the impact of social relationships is in fact significant with the overall effect size corresponding to a 50% increase in odds of survival in those persons with positive social relationships.

The protective effects of well-being are also well represented in the literature. Chida and Steptoe (2008) reported an association between positive affect and reduced mortality in both healthy and diseased groups independent of negative affect, as well as reduced mortality in patients with renal failure or human immunodeficiency virus infection. Multiple studies demonstrated protective links to cardiovascular indicators (Chida & Steptoe, 2008; Davidson, Mostofsky, & Whang, 2010), including Ryff et al. (2004), who found lower total cholesterol/HDL cholesterol ratios, lower weights, and lower levels of glycosylated haemoglobin in persons with high levels of eudaimonic well-being.

Positive emotion has been found to be associated with longevity in several prospective studies with elderly, international populations (Koopsmans, Geleijnse, Zitman, & Giltay, 2010; Ostir et al., 2000). Blazer and Hybels (2004) studied individuals over the age of 65, measuring positive and negative affect using the Center for Epidemiologic Studies Depression (CESD) scale at baseline and at 10-year follow-up. Those who had scored lower on the positive affect scale were significantly more likely to have died within the 10-year period. These results suggest a protective effect of high positive affect for older individuals.

Danner, Snowdon, and Friesen (2001) reported results of the Nun Study, a longitudinal study of aging and AD of 678 members of the School Sisters of Notre Dame religious congregation born before 1917 (Snowdon, 1997; Snowdon et al., 1996). Of these, handwritten autobiographies of 180 Catholic nuns written at approximately age 22 were reviewed for positive emotional content and compared to risk of mortality in late life. Results indicate a very strong association between positive emotions expressed in the autobiographies and longevity after six decades. Data from the prospective studies

suggest a positive influence of well-being on health, but the evidence is entirely correlational and it is possible that unidentified and unmeasured variables may account for the results. Additional variables are possible in each of the studies reviewed and need to be evaluated in future research.

Finally, Ashby and Isen (1999) present evidence that positive affect facilitates recall and is associated with improved creative problem-solving. The authors posit that increased levels of dopamine in frontal cortical areas corresponding with positive affect influence cognitive processing. According to the dopaminergic theory, patients taking dopamine antagonists may have impaired working memory, diminished cognitive flexibility, and creative problem-solving ability. This is highly relevant in AD care, where dopamine antagonists are at times prescribed for the treatment of hallucinations and behavioral deregulation.

As evidenced in this review, previous studies have reported that well-being correlates with improvement in biological markers and psychosocial factors and provides protective benefits, longevity, and better cognitive processing. However, few studies have included persons with AD. The assumption that happiness and well-being positively affect physical, psychosocial, and cognitive health in the context of AD follows on from these studies with subjects who are not diagnosed with AD, yet the link in the specific case of AD patients remains unforged.

While knowledge of the benefits of positive emotion for physical health adds to the significance of this study, these results are hampered by the reductionist definitions of happiness and the resulting challenges to construct validity. However, the aim of this research is not to find causal explanation of happiness or well-being, or that it is even a

measurable construct. Rather, the intention of this research is to understand from the subjective perspective how people with AD experience happiness.

Measures of Well-Being in Quality-of-Life Tools

The increased interest in the development of interventions aimed to improve the quality of life in AD was accompanied by attention to outcome measures and the need for tools to evaluate the effectiveness of treatment. The work of M. Powell Lawton (1983, 1994) was a major influence on the conceptualization of quality of life in AD. His work stressed a multidimensional evaluation of AD requiring both subjective and objective appraisal. Subjective quality of life refers to the individual's own ideas about his or her life with a focus on psychological well-being, including happiness, morale, and self-esteem. The conceptual framework developed by Lawton (1994) identifies four dimensions, including: (1) generalized psychological well-being, which Lawton describes as one's overall evaluation of "self in environment" (p. 139) and which consists of affective states including depression, anxiety, and happiness; (2) objective environment, which refers to scheduled events and physical surroundings; (3) behavioral competence, including functional, social, and cognitive ability; and (4) perceived quality of life. Lawton believed that measurement of subjective quality of life is "usually foregone" for the patient with AD that has progressed beyond mild, stating that "cognitively impaired patients do not introspect, or at least do not report reliably on, interior phenomena" (p. 139). Many of the current AD quality of life measures are based on the work by Lawton. I have selected four measures for review because they were designed for use in community settings in persons with mild to moderate AD, the population represented in my study. They include Brod, Stewart, Sands, and Walton's (1999) AD Quality of Life

Instrument (DQoL); Logsdon and Albert's (1999) Quality of Life in Alzheimer's Disease (QoL-AD) tool; Rabins and Kasper's (1997) Alzheimer's Disease-Related Quality of Life (ADRQL) instrument; and Ready and Ott's (2003) Cornell Brown Scale (CBS) for Quality of Life in AD.

Brod et al. (1999) created the DQoL, a 29 item scale for use in mild to moderate AD. Information for instrument development was gathered through a literature review and from three focus groups, each composed entirely of either live-in caregivers, healthcare providers, or persons with early-stage AD. From this information, a comprehensive, AD-specific definition of quality of life was developed inclusive of domains meaningful to those with a mild to moderate cognitive impairment. The DQoL includes five scales to assess subjective quality of life: self-esteem, positive affect, negative affect, feelings of belonging, and sense of aesthetics. Six items are used to measure positive affect. The respondent is asked to identify the frequency she or he felt cheerful, content, hopeful, found something that made him or her laugh, jokes, or laughs with others. Three types of reliability were examined by the authors: item test-retest, internal consistency for multi-item scales, and 2-week test-retest. The coefficient used to assess item test-retest reliability was chosen based on the scale distribution. The Pearson product-moment coefficient was selected for multi-item and continuous scales with five or more levels, Phi for dichotomous scales, and Kendall's tau for scales with less than five levels. Immediate time test-retest was based on the readministration of selected items at the end of the interview, with scores ranging from 0.54 to 0.62. Two-week test-retest correlation scores ranged from 0.64 to 0.90. Cronbach's alpha was used to determine internal consistency reliability, with scores ranging from 0.67 to 0.89. Construct validity was tested and confirmed by assessing correlation of the negative affect subscale with

scores on the Geriatric Depression Scale and correlations among the scales in each domain. Adequacy of the hypothesized scales was assessed by examining correlations of the items within the scale. The authors conclude that persons with mild to moderate AD are able to report their own subjective states.

Rabins et al. (1997) created the ADRQL for use in all levels of AD. The domains of the 47 true-or-false response instrument (ADRQL) are based on information obtained from proxy respondents (caregivers, healthcare providers, and experts in the field of AD) and a review of the literature. Five domains are included in the ADRQL: social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surroundings. The final step involved cognitive interviews with a sample of caregivers to ensure the items were understood by the caregivers. Utilizing the ADRQL, the caregivers assess the quality of life for the person with AD by observing behaviors for each domain. No subjective information is gathered from the person with AD due to the view of the authors that individuals with AD were unable to make assessments of health-related quality of life issues.

Logsdon and Albert (1999) created the QoL-AD, a 13 item measure including both patient and proxy report. The QoL-AD includes five domains: physical condition, mood, interpersonal relationships, ability to participate in a meaningful way, and financial situation. Items for the QOL-AD were selected based on a literature review of quality of life in geriatric populations. Items were then reviewed by patients with AD, their caregivers, and experts in the field of gerontology to ensure content validity (Logsdon & Albert, 1999; Ready & Ott, 2003). The QoL-AD scale asks the respondent to rate “mood” and “life as a whole” as poor, fair, good, or excellent. No item directly refers to happiness. Logsdon and Albert (2002) used the QoL-AD to assess quality of life in

persons with mild- to moderate-stage AD. In addition to the QoL-AD, the 155 participants were also judged on measures of behavioral competence using the Physical and Instrumental Self-Maintenance Scale and the Revised Memory and Behavior Problem Checklist; physical functioning as measured on two subscales of the Medical Outcomes Study; psychological status using the Geriatric Depression Scale and the Pleasant Events Schedule-AD Short Form; and interpersonal environment indicated by caregiver burden and measured on the Screen for Caregiver Burden and the Center for Epidemiologic Studies Depression Scale (CESD), both administered to the caregiver. Results included the coefficient α scores of ≥ 0.80 for both patient and caregiver reports of quality of life, indicating good internal consistency in patient and caregiver reports on the QoL-AD. To determine validity, the associations between patient and caregiver reported QoL-AD scores and measures representing the hypothesized quality of life domains of behavioral competence, physical functioning, psychological status, and interpersonal environment were evaluated using Pearson correlation coefficients. Based on these results, Logsdon and Albert (2002) concluded that persons with mild- to moderate-stage AD can provide a subjective assessment of their quality of life.

Ready, Ott, Grace, and Fernandez (2002) created the CBS for Quality of Life in AD by modifying the Cornell-Brown scale for Depression in AD. The CBS incorporates patient and caregiver perspectives into one rating on a 19 bipolar-item scale with each item scored -2 to +2, representing four domains: positive affect, negative affect, self-esteem, and satisfaction. The CBS is clinician-rated after a joint semistructured interview with the patient and caregiver. The scale was developed based on the concept that high quality of life is indicated by the presence of positive affect, physical and psychological satisfaction, self-esteem, and the absence of negative affect and negative experiences. Of

the 19 questions, one asks the respondent to rate his or her mood on a continuum from sad (-2) to happy (+2) (Ready & Ott, 2003; Ready et al., 2002).

The four scales reviewed were chosen for their appropriateness for use in the population to be studied. Of the four, only one, the DQoL, was based on information obtained by persons with AD along with caregivers and healthcare providers. Respondents for the DQoL were the persons with AD, while respondents for the ADRQL were proxy caregivers only. Both the QoL-AD and the CBS measure responses from both caregiver and patient. All four measures contained mood or positive affect domains and had an internal consistency of 0.80 or greater for either the total scale or the positive affect subscale. Of the four scales, one assessed mood by observing behaviors, eliciting no verbal information for the subject. One evaluated "mood" on a range from +2 to -2, and one assessed "mood" and "life as a whole" as poor, fair, good, or excellent. Only the DQoL, the tool developed with input from persons with AD, listed more than two items as a measure of positive affect; cheerful, content, hopeful, found something that made them laugh, jokes, and laughs with others. Only one of these identified items, content, was reported in the qualitative studies previous reviewed.

The variation in the method used to develop the tools reviewed here explains in part the differences in the items and the domains included in the measures, important given that their usefulness depends on the dependent variable being a reliable and valid measure of the concept, a fact that has not been clearly established. Proxy ratings of quality of life are part of the assessment in three of the reviewed tools and the exclusive source of information in one. However, it is increasingly recognized that proxy ratings underestimate quality of life as compared to the care recipient with AD (Novella et al., 2001). Additionally, the measures reviewed are limited by the oversimplification of the

concept of quality of life upon which they are derived. Only one tool uses more than two items to measure a concept as broad and complex as positive well-being, highlighting the inadequacy of the reductionist approach found in these measures. While these studies offer a picture of quality of life created with a broad stroke, the nuances of what really matters to the individual and that can best be obtained from individual subjectivity is missing. Although these measures provide a subjective assessment, all of which include some component of positive affect and provide some information regarding happiness, concepts have been reduced and address only limited psychosocial features. Thus, the quality of life measures fall short of providing a thorough understanding of the subjective experience of happiness.

The Challenge of Retrospective Life Review: Two Perspectives on One Life

Studies that examine quality of life in persons with or without AD assume that the individual can meaningfully answer questions about feelings. While reporting current emotions is relatively straightforward, remembering and evaluating past events requires introspection, the ability to retrieve past emotions, and the ability to integrate experiences that may have occurred over many moments to determine a response that represents the "average" of the moments (Kahneman & Riis, 2005). Kahneman and Riis (2005) describe an individual's life as a series of moments, each of which last up to three seconds and then disappear but some of which can be retrieved at a later time. They use the term the *experiencing self* to signify the individual's appraisal of a moment as it is happening and *remembering self* to indicate a retrospective viewpoint.

Ability to recover feelings and to integrate experiences that are spread over time is required to appraise past events; both are prone to error and less trustworthy than evaluations made as the event is unfolding (Kahneman & Riis, 2005). The remembering self therefore may not accurately represent the actual experience. Fredrickson and Kahneman (1993) reported that when asked to judge a past event, the person creates a representative moment of the experience through averaging the affect experienced during the most extreme moment (peak) and the affect experienced near the end, a process referred to as the Peak-End rule. Kahneman (2000) suggests that duration neglect, the duration of either positive or negative affect, has minimal effect on the memory of the experience. It is this representative moment created using the Peak-End rule, with disregard for the duration, that provides the "snapshot" used to evaluate past experiences. But does that snapshot represent the actual experience?

In a study by Kahneman, Fredrickson, Schreiber, and Redelmeier (1993), participants immersed one hand in painfully cold water twice. One trial lasted 60 seconds, with water temperature 14° C. The other trial lasted 90 seconds, with water temperature at 14° C for the first 60 seconds and then gradually increased to 15° C during the final 30 seconds. The participants were later given a choice to repeat either trial. A significant majority of subjects chose to repeat the longer trial. Although counter-intuitive, this supports the Peak-End rule, which suggests adding a period of reduced discomfort to a more unpleasant episode will result in a more favorable evaluation of the episode. While the choice of extending pain appears illogical, it is explained by the concept of duration neglect, indicating that duration of the positive or negative event has little effect on the memory (Fredrickson & Kahneman, 1993).

Kahneman (2000) termed the paradoxical effect of improving the memory of an event by adding a period of lesser pain to lower the Peak/End average *violations of dominance.* Violation of dominance was also observed in an experiment that exposed participants to two loud, unpleasant sounds. One lasted 10 seconds at 78 decibels (dB), while the other started with the same 10 seconds at 78 dB followed by 4 seconds at 66 dB. As in the previous example, participants were asked to choose which of the two sounds would be repeated later. Significantly more participants chose the longer option, as the Peak/End rule and duration neglect would suggest (Schreiber & Kahneman, 2000).

The studies by Kahneman and others reported here highlight the difficulty in using retrospective evaluations of individuals to assess an experience, irrespective of the presence of a brain disease such as AD. This suggests that our approaches to studying happiness should be revised to focus on the present, on the experiencing self. This is especially true in the study of AD, a disease in which difficulty in short-term memory reflects the physiological and experiential nature of AD and contributes to the loss of personhood for the individual. Additionally, the suggestion that memory is vulnerable in all persons and not just those with AD separates our assumptions about recall and the concept of personhood, and refigures it in ways that are inherently less pathologizing for people with AD.

For these reasons, the questions posed in this study were asked in the present tense (what makes you happy *now?)*, and the time frame between taking the pictures and the interview was approximately two days after the pictures were taken. The first 4 participants took representative pictures of happiness in the company of the caregiver. I accompanied the remaining participants so that I could document the thoughts and reasons behind each picture taken.

Conclusion

In this review of the literature, the development of the concept of AD from its roots in the biomedical tradition has been presented. In addition, theories of happiness in the aged have been reviewed, including the lack of consensus and the reductionist representation of its construct in the context of AD, and the difficulty of the retrospective assessment of happiness in those both with and without AD. Given the challenges presented here, a design that embodies these insights, including open-ended questions and interview, was developed to assess the current level of happiness of persons with AD and is presented next.

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CHAPTER 3

THEORETICAL AND METHODOLOGICAL FRAMEWORK

Introduction

In this chapter, I will articulate the specifics of the theoretical orientation that guide this study: symbolic interactionism, positive psychology, and Kitwood's theory of personhood. I will explain how these fit together to support my purpose and aims. I will then identify those aspects essential to my study of *wellness within illness* and articulate my own assumptions that will serve as the basis of my study

Social Constructionism and Symbolic Interactionism

To understand the experience of happiness and subjective well-being in persons with Alzheimer's disease (AD), I will begin with a constructionist epistemology. I chose the interpretive approach symbolic interactionism to frame my work. Constructionist epistemology states meaning is derived from our engagement with the world and reflects the understanding of one's experiences in the context of their environment (Crotty, 1998).

The constructionist view informs the symbolic interactionist approach. Originally developed by George Mead and expanded on by Herbert Blumer, symbolic interactionism assumes that human beings assign meaning to their circumstances and their environment, and that these meanings are derived from interaction with others (Schwandt, 2001). Symbolic interactionism emphasizes the importance of subjective meaning in the study of human behavior as it is derived from social interaction and

context (MacRae, 2010). It also assumes the primacy of social meaning, whereby the social processes comes first, and from these processes subjective understanding and meaning is derived. Thus, symbolic interactionism is primarily intersubjective, making it an appropriate choice to address the purpose and aims of this study of subjective and intersubjective well-being in AD.

While symbolic interaction will serve as the grand theory, supplying a specific set of assumptions upon which this research is based, Kitwood's theory of personhood and positive psychology will function as midrange theory, providing propositions for the framework that informs my research question and aims and the lens through which I will interpret the utility and implications of the findings. I begin with a review of specific theories upon which my study was informed and designed.

Kitwood's Psychosocial Model of AD

The biomedical model (reviewed in Chapter 2) is the dominant lens through which AD is currently viewed; it has been criticized for minimizing the importance of the whole person by omitting the psychosocial factors that affect the individual. In contrast, the work of Kitwood (1989, 1997) broadens the focus, highlighting the importance of the psychosocial perspective and the impact of the social context within which persons with AD live their lives.

Kitwood criticized the biomedical model, which he called the "standard paradigm," believing it failed to represent dementia fully by focusing on the treatment of symptoms. Kitwood (1989, p.1) represented the standard biomedical paradigm of AD as a causal linear design:

X (physical phenomenon) ⟶ neuropathic change ⟶ AD

In the case of AD, the *X* that represents the cause remains uncertain.

In contrast, Kitwood believed each event experienced by a person with AD has both a psychological and biological component, and the interplay between these two factors and the social environment produces the symptoms associated with AD. This belief is the basis of Kitwood's "dialectic framework for dementia," in which he suggests that not only do psychosocial factors contribute to the development of dementia, but they also constitute threats to one's personhood (1990). According to Kitwood, the negative interactions of others including caregivers, results in the loss of personhood in people with dementia. Kitwood believed we need to reconceptualize dementia and dementia care by recognizing the person with dementia as a sentient social being deserving of a central position within person-centered care (Kitwood, 1989; 1997).

Kitwood's Theory of Personhood

Emerging through the work of Tom Kitwood and Kathleen Bredin (1992), personhood challenges the biomedical paradigm of dementia focused on pathology, decline, and loss, which has led to the labeling of persons with dementia. Kitwood (1997) defined *personhood* as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p.8) and encompasses the domains of physical, psychological, spiritual, and social aspects of self. Kitwood believed the concept of personhood is essential to ensure the respect of the person's humanity in the presence of dementia, both in daily interaction with the individual as well as in planning care for people living in long-term care. It was Kitwood's view that if the psychological and social needs of an individual were met, a

person could attain a high level of well-being even in the presence of dementia (Kitwood, 1997).

Assumptions of Kitwood's Theory of Personhood

According to Kitwood (1997), it is the reactions of others to the loss of ability within a particular social context that places personhood at risk. The meaning assigned to each domain—physical, psychological, spiritual, and social—as well as the response to reduction in that domain is unique for each individual and is culturally bound. Sterin (2002) brings Kitwood's theory of the interconnectedness of human beings to life in her writing about her own personal experiences with AD, in which she describes her treatment by others: "People simply stop talking to you in the way that they used to. You are in a different category from the normal population" (Sterin, 2002, p. 8).

Kitwood (1997) believed that the losses and difficulties in later life, including AD, are therefore socially constructed. Kitwood (1997) argued that the personhood of people with AD is at risk of being undermined through a dialectical interplay between neurological changes in brain function and exposure to "malignant social psychology" that further worsens the psychological burden on people with AD. Kitwood (1997) identifies malignant social psychology as the processes and interactions that may adversely affect an individual's self-esteem and lead to the diminution of personhood, such as stigmatization that labels a person as different or banishment that removes the individual from social settings when their presence becomes uncomfortable to others. Regardless of whether malignant social psychology occurs with conscious intent, Kitwood (1997) believes it to be part of our culture and a part of everyday interaction.

Kitwood also assumes the existence of a "core self" that remains no matter how severe the losses associated with AD. This core self can be reached through interaction with others (Baldwin & Capstik, 2007, p. 89). Kitwood presumes personhood is supported by having five fundamental needs met: comfort, attachment, inclusion, occupation, and identity (Kitwood 1997, p. 81). Just as personhood can be undermined by the malignant social psychology, it can also be supported by positive exchanges with others that lead to having one's needs met. In this way, Kitwood assumes that a person with AD can experience well-being if his/her needs are met. If the level of human interaction is very high, well-being will be further enhanced.

Kitwood challenged the biomedical model of AD that he believed focused on pathology and symptomatology. Through his work, he expanded our understanding of AD beyond tangles and plaques to include psychosocial factors that may impact the development and progression of the disease. Kitwood also challenges us to consider what it means to be human; what determines which behaviors are normative, non-normative behaviors, or unique expressions of one's self; and what role those without AD play in the "problems" of those with AD. Unfortunately, Kitwood died before exploring the role of happiness and positive emotion in the experience of AD.

Positive Psychology

Like Kitwood's theory of personhood, positive psychology also challenges the biomedical model by expanding our understanding of disease to include building and strengthening one's positive attributes, including happiness. In Martin Seligman's 1999 presidential address to the American Psychological Association, building on the work of Abraham Maslow, he suggested attention should be paid to an individual's strength and

resolved to initiate a shift in psychology's focus toward a more positive psychology (Seligman, 1999).

"Positive psychology is the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions" (Gable & Haidt, 2005, p. 104). The goal is not to erase or replace work on pathology and dysfunction. Instead, the goal is to include knowledge about human resilience, strength, and growth to complement existing knowledge and then use this knowledge to develop interventions to support these processes (Duckworth, Steen, & Seligman, 2005; Gable & Haidt, 2005). Hence, the field is concerned with well-being, optimal functioning, and enabling people to be at their best. In this study of happiness in an individual with AD, the aim is not to deny the neurodegenerative process that occurs but rather to broaden our understanding to include the recognition of areas of wellness that may also occur and build on strengths that may be present but that would otherwise go unrecognized or undervalued. It is my belief that this would allow for maximum functioning and optimal health and quality of life, even in the face of AD.

An understanding of the role of positive emotions such as happiness in AD remains unclear. The Broaden-and-Build Theory of Positive Emotions (Fredrickson, 1998; Fredrickson & Cohn, 2008) suggests that positive emotions can result in greater flexibility in thinking, improve problem-solving skills, and provide increased social resources for the individual (Ong, Bergeman, Bisconti, & Wallace, 2006). For example, the positive emotion of affection may result in a lasting supportive relationship, which in turn may lead to additional personal resources that may improve health and longevity (Cohn, Fredrickson, Brown, & Mikels, 2009). Research suggests that positive emotion is

associated with increased resilience (Fredrickson, 2001; Fredrickson, Tugade, Waugh, & Larkin, 2003; Lyubomirsky, King, & Diener, 2005; Tugade & Fredrickson, 2004). A recent study by Cohn et al. (2009) found that positive emotions predicted increase in resilience and life satisfaction in students. However, little is known about the relationship between positive emotion and resilience to stressful late-life events or diseases such as AD.

In fact, few studies have applied the concept of positive psychology to persons with AD. Harris and Keady (2008) advocate changing the language of AD by pairing words related to Alzheimer's disease—such as *AD* and *caregiver*—with positive images. This attempt to broaden the public perception of AD can be effective only if it is grounded in research that supports the possibility of such a link. To this end, I will look at happiness in the presence of AD from the vantage point of the work by Fredrickson, Seligman, and others in the field of positive psychology. In this way, my study aims to move forward our understanding of the role positive emotion such as happiness plays in AD.

Assumptions of Positive Psychology

The assumption that virtues such as human goodness and excellence are as authentic and important as disease, disorder, and distress lies at the foundation of positive psychology. Virtues play a significant role in positive psychology; the identification and measurement of these qualities serves as a framework used to identify personal strengths (Peterson, 2006). The second assumption—that positive experiences and traits are not necessarily the opposite of negative states or traits—suggests that amelioration of negative affect does not in and of itself result in positive affect. Duckworth et al. (2005)

demonstrates this point by noting that relief of suffering does not in itself lead to well-being but rather removes an obstacle to well-being. The third assumption of positive psychology is that emotional well-being will be accompanied by optimal functioning of multiple physiological systems and that subjective well-being is essential to health (Ryff, Singer, & Love, 2004).

Comparison of Biomedical Model, Kitwood's Theory of Personhood, and Positive Psychology

In Appendix A, "Comparison of Biomedical, Kitwood's Theory of Personhood, and Positive Psychology," positive psychology and the biomedical model are compared and contrasted for underlying assumptions and conceptualization of health, illness, well-being, and AD as well as the role of the "other." Looking across the rows, one is able to see the significant change in the depth and complexity of understanding of wellness and illness that occurs when moving from left to right.

In Appendix A, the expansion of the biomedical model by positive psychology is found in the inclusion of personal strengths and resilience in the understanding of the individual, with the expectation that an improvement in physical functioning will follow. Adding the perception of positive psychology broadens our understanding of an individual. Knowing the strengths and virtues of a person allows an opportunity to build resilience and encourage adaptation and acceptance of challenges associated with chronic illness such as AD. Identifying the presence of subjective well-being and happiness is life-affirming, challenging the stigma of an individual with AD being no more than a "shell" of a person and encouraging interaction with the environment, which leads to cognitive stimulation.

Not all is positive with positive psychology. First, positive psychology focuses heavily on the individual rather than considering the impact of the family, society, or, in the case of AD, the caregiver. Second, while Seligman and Steen (2005) and others have described positive psychology as a supplement to the current illness paradigm, there remains a concern that positive psychology ignores the negative factors that affect health (Lazarus, 2003). Some view positive psychology as an overly positive view of life that ignores problems and challenges such as chronic illness. Indeed, no study of positive psychology has included individuals with AD. Third, describing positive psychology as a "supplement" is troubling in that it reflects a dichotomous view of positive and negative traits, which I believe denies integration of both poles as occurs in day-to-day living.

Kitwood's theory of personhood addressed the role of the "other" more fully, implicating social support and human interchange in both the development and treatment of AD. However, Kitwood offered no clear understanding of the meaning of well-being or happiness, instead identifying outward signs indicative of the presence of well-being (Baldwin & Capstick, 2007). The indicators—including showing pleasure, helpfulness, and initiation of social contact (Kitwood, 1992, p. 140)—point to behaviors that reflect compliance, suggesting that Kitwood's view of happiness was less about pleasure and more about acceptance (Baldwin & Capstick, 2007). In addition, assuming the presence of well-being from observed behaviors is problematic due to the risk of misinterpretation. Helpfulness may be the result of anxiety or fear rather than well-being. Kitwood's work on AD was an ongoing work at the time of his death, and perhaps his concept of happiness and well-being might have been expanded if he had not died suddenly. It appears Kitwood left behind an incomplete appraisal of the experience of happiness in an

otherwise vast body of work that challenged the customary medical discourse of AD in the 1970s. This study hopes to fill some of the omissions remaining in Kitwood's theory.

While both the theory of positive psychology and personhood offer keen insight into AD, both also are missing key pieces of interest for my study. Positive psychology offers a structure useful to the understanding and studying happiness, yet it is lacking an orientation of the person in the context of a larger community. Kitwood stresses the social role in AD but provides limited information pertaining to happiness. Each theory addresses the gaps left by the other, and together these theories provide a sound framework upon which to base my study.

Wellness within Illness

Although it is commonly recognized that a relationship exists between wellness and illness, exactly what this relationship is has not been clearly explicated. In addition, there is little agreement regarding the meaning of the concepts themselves. Dunn (1959) coined the term *wellness* as the "integration of both people's capacity to function in their environment, and their ability to adjust to environmental stresses" (Boruchovitch & Mednick, 2002, p. 176). In this definition reflecting an ecological concept of health, emphasis is placed on the interrelationships between the environment and the individual's ability to adapt, although a clear delineation of healthy versus unhealthy adaptation is not developed (Boruchovitch & Mednick, 2002). More recently, *wellness* is used synonymously with *health*.

As with *health*, the meaning of *illness* has changed over time from something caused by evil spirits to merely a state of nonhealth. Two main views of disease are prevalent today: (1) disease as a separate entity that befalls a healthy person, and (2)

disease as a deviation from the norm (Jensen & Allen, 1993). In a model proposed by Jensen and Allen (1993), wellness-illness is thought to be affected by intrapersonal factors, such as personality and past experiences; interpersonal factors, such as social supports and relationships; health- and disease-related factors, such as functional status and disease severity; and extrapersonal factors, such as cultural and economic status. Viewed as part of a whole rather than as mutually exclusive, the individual moves between both health and illness and can "achieve wellness by accepting disease as an integral part of oneself" (Jensen & Allen, 1993, p. 221).

While a focus on wellness is common in community health and other healthcare settings where the clients are primarily healthy, it is less commonly considered in the context of acute or chronic illness. Yet, while the notion that people can experience wellness despite their illness may at first seem counterintuitive, studies have shown that it does happen, even in the face of serious illness. In a longitudinal study of caregiver partners of persons with acquired immune deficiency syndrome (AIDS), Folkman (1997) found that not only did the caregivers report high levels of negative psychological states but also high levels of positive psychological states during both the caregiving and bereavement periods. Additionally, the concept of health within illness as applied to cancer patients has been cited frequently in the nursing literature as a way to reconceptualize illness as a mechanism for growth (Moch, 1998).

The concept of wellness within illness may seem especially difficult to grasp in AD due to the neurodegenerative symptoms and downhill progression of the disorder as well as the associated belief that the individual is incompetent. The use of proxy reports from caregivers, such as those commonly used to assess issues related to quality of life,

reinforces the belief that individuals with AD are unreliable or without ability to effectively communicate or self-report (Beard, 2004). The difficulty in reconciling wellness within illness may also result from the presence of non-normative behaviors that reinforce the individual's position as "sick" and makes the idea of wellness seem incompatible.

Yet if attention is paid to wellness within AD, a more holistic understanding of the disease itself may emerge, allowing for the possibility of happiness, growth, adaptation, and acceptance, emphasizing individual strengths while lessening the social isolation that comes with presumed deterioration and loss of communication and cognition. Possible benefits may include the maintenance of personhood, a decrease in depression commonly associated with AD, changes in interpretation of behaviors (if wellness is conceptualized as the presence of desirable behaviors such as purposeful walking to meet a need rather than the absence of non-normative acts such as pacing), and development of personalized interventions that will enhance quality of life for the individual. Brod (1999) noted that many AD patients and their spouses have described improvements in their relationships since receiving the diagnosis of AD. Including wellness in the picture of AD changes the paradigm from one of despair and loss to one that includes the possibility of happiness, adaptation, and acceptance.

Assumptions in My Study of Wellness within Illness in AD

My research recognizes the determinism of the biomedical model, currently the prevailing view of AD. Grounded in Tom Kitwood's theory of personhood and utilizing

concepts from positive psychology, my study focuses on the experience of happiness in persons with mild to moderate AD.

Assumption #1: Happiness Entails More than Positive Affect

I assert that the theories of happiness identified in Chapter 2 do not capture the full construct of happiness or subjective well-being. I present here the concepts of eudemonia and "state versus trait" theory to highlight what I believe to be missing from the construct of positive affect.

Eudemonia

In the *Nicomachean Ethics*, written by Aristotle and intended to help readers become good rather than simply reflect on a good life, Aristotle defines *eudemonia*, a Greek word frequently translated as happiness or well-being, as the highest goal a person can strive to attain. As explained by Waterman (1993), *eudemonism* is an ethical theory of individuals living according to their *daimon*, which refers to the greatest fulfillment. Eudemonism is a theory of self-realization and represents the feelings that accompany the attainment of one's true potential.

According to Aristotle's view of eudemonia, each individual comes into life with unique capacities; one's daimon and the central task of life is to recognize and realize these talents. Ryff and Singer (1989) operationalized eudemonia into six dimensions of well-being: self-acceptance, purpose in life, positive relations with others, environmental mastery, personal growth, and autonomy. The concept of eudemonia suggests that there is more to life than the presence of pleasure: there is also authenticity, affection, vitality, good spirits, and utilization of one's full potential.

State Happiness versus Trait Happiness

Another theory of happiness is that it is a fixed "trait" rather than a variable "state." As a trait, happiness would be viewed as a stable disposition toward life that could not be significantly altered by any change in living conditions but rather would contribute to stability over time and across situations. Seen as a state, happiness is considered to be more reactive to a particular situation. According to Veenhoven (1994), happiness can be regarded as a trait if it meets three criteria: temporal stability, cross-situational consistency, and inner causation. In a 1993 meta-analysis of longitudinal studies, Veenhoven (1994) tested the theory that happiness is a trait, concluding that (1) happiness is stable in the short term, but not in the long term; (2) happiness is not situationally consistent, but rather affected by improvement or deterioration in life; and (3) happiness is not entirely internal, having in fact only a modest genetic effect. In short, Veenhoven concludes happiness does not meet the three definitions of a trait.

My assumption of happiness is informed by the concept of eudemonism as well as the concept of happiness as a state. Aristotle's theory of eudemonism effectively separates happiness from narrower constructs like affect, mood, and domain agreement, which in turn results in an understanding of well-being that is content limited. Instead, eudemonism strives toward self-actualization and attainment of one's true potential. Together with the concept of state happiness, which implies that change is possible, both concepts support the development of interventions to improve external living conditions in an effort to achieve greater happiness and self-fulfillment.

Assumption #2: Happiness Is Associated with Physiologic and Psychosocial Health of Persons with AD

The core hypothesis of positive health has been identified as the contribution of well-being to the maintenance or restoration of health and physical functioning of an individual (Ryff et al., 2004). Although the measured constructs of positive emotion vary between studies, sufficient evidence does exist to suggest an association between well-being and physical and psychosocial health. These studies, which were reviewed in Chapter 2, have reported that well-being correlates with improvement in biological markers and psychosocial factors and provides protective benefits, longevity, and better cognitive processing. However, few studies have included persons with AD. The assumption that happiness and well-being positively impact physical, psychosocial, and cognitive health in the context of AD follows on from these studies with nondemented patients, yet the link in the specific case of AD patients remains unproven. While knowledge of the benefits of positive emotion adds to the significance of this study, the aim of this research is not to find causal explanation of happiness or well-being, or to prove that it is even a measurable construct. Rather, the intention of this research is to understand from the subjective perspective how people with AD experience happiness.

Assumption #3: Individuals with Mild to Moderate Alzheimer's Disease Have the Capacity to Make Judgments about Their Lives

It is generally believed that persons in the early stages of AD are by and large able to self-report their inner emotional states but that as the disease progresses, cognitive

impairment makes communication more difficult (Kwasky, Harrison, & Whall, 2010). Measures have been developed and validated that incorporate views from people with AD and provide evidence that people with AD can comment meaningfully about quality of life (Brod et al., 1999; Logsdon et al., 2002; Smith et al., 2005; Thorgrimson et al., 2003). Two of these studies, Brod et al. (1999) and Logsdon et al. (2002), were reviewed in Chapter 2 and demonstrate the ability of persons with mild to moderate AD to report their own subjective state.

Yet due to the neurodegenerative symptoms of AD and downhill progression of the disorder as well as the associated belief that the individual is incompetent, proxy reports from caregivers have been and continue to be used to assess issues related to quality of life. This practice reinforces the belief that individuals with AD are unreliable or without ability to effectively communicate or self-report (Beard, 2004). Research has found discrepancies in the quality of life ratings given by the caregiver as compared to the ratings given by the person with AD. In a study by Sands, Ferreira, Stewart, Brod, and Yaffe (2004) of 91 dyads, the person with AD rated his or her quality of life higher than did his or her caregiver in five domains—self-esteem, positive affect, negative affect, feelings of belonging, and sense of aesthetics. These findings of incongruity in the responses of caregivers and AD patients have been replicated in other studies (Ready et al., 2004; Spector & Orrell, 2006) and highlight the fact that whether the assessment originates from the patient or is filtered through the perspective of the caregiver, both are subjective and therefore vulnerable to questions of validity. Shadish, Cook and Campbell (2002) identify the belief that there is no reason to look for a single truth or answer as there are multiple realities and multiple truths as one challenge to validity (p. 482).

Multiple realities and multiple truths may be present and can be either conflicting or consensual (Shadish et al., 2002).

Qualitative research seeks to understand the subtle nuances of the lived experience; therefore, the evaluation of the care receiver's quality of life from either member of the dyad may be valuable, depending on the researcher's question (Whittemore et al., 2001). The focus of this study is the subjective experience of the individual with AD, so the voice of the care recipient must be included.

Assumption #4: Wellness within Illness is Possible in Alzheimer's Disease

Symbolic interactionism assumes that experience and meaning arise out of intra- and interpersonal transactions organized around symbols that hold and transmit meaning for individuals within social and cultural networks. From the vantage point of symbolic interactionism, the individual and society are inseparable, and an understanding of one requires an understanding of the other (Crotty, 1998). Individuals make sense of themselves and of their position in society through their interactions with others and in shared symbols. In this way, social interaction functions as the building block of society, creating and confirming social patterns or isolating individuals outside the interaction (Charon, 2009).

According to George Herbert Mead, architect of symbolic interactionism, humans exist in a world of objects around which activities are structured (Blumer, 1966). The nature of the object is determined by the meaning it has for the individual, and that meaning is derived from the interaction of the person to the object rather than from fundamental properties of the object. In this way, an object may be anything to which an

individual can refer, including physical items such as the computer on which this sentence is being written, or as abstract as the concept of happiness or wellness within illness (Blumer, 1966). Since all meanings are developed contextually through social interaction rather than being intrinsic to the object, it follows that objects vary in their meaning. In this way, persons construct their own subjective happiness in and through historical and contextual experiences (Blumer, 1966; Crotty, 1998).

The subjective view of the individual is of primary importance based on the assumption of symbolic interactionism that one can appreciate an individual's actions and experiences only by understanding reality as it is perceived by the individual (MacRae, 2010). Looked at from a constructionist epistemology, a subjective sense of eudemonic happiness as theorized by Aristotle and wellness within illness are both shaped in and through everyday interaction with symbols such as memories or by social interaction in the moment—both possible for the individual with AD.

Methodological Framework

In this section, I will articulate the specifics of my methodology as informed by symbolic interactionism, principles of interpretive theory, and photo elicitation as a method of data collection. I will also orient the reader as to how these fit together to support my purpose and aims.

Symbolic interaction falls under the umbrella of interpretivism (Crotty, 1998). As previously described, symbolic interaction presumes humans exist in a world of objects, the nature of which is determined by the meaning the object has for the individual; the object may be anything to which an individual can refer (Blumer, 1966). In this study, happiness is symbolic—we symbolize it to ourselves and each other, and the symbolic

meaning constructs the experience. Symbolic interactionism invites the researcher to look closely at the research participants' interpretations of their actions and situations, including happiness (Charmaz, 1990). In this study, supported by the underpinnings of symbolic interactionism, photographs and the interviews describing their meaning were the symbolic representations analyzed to gain access to individual's interpretation of well-being. The narratives obtained during the interviews with participants were analyzed using interpretivist theory methodology.

Interpretivist Approach to Inquiry

According to Denzin and Lincoln (2000), there are four major paradigmatic structures in research: positivist/postpositivist, constructivist/interpretive, critical, and feminist/poststructural. Schwandt (2001) asserts that although the term *interpretivism* is sometimes used to refer to all qualitative methods, it more accurately refers to approaches to study the social life. Interpretivism assumes the meaning of human action is inherent in that action, and the task of the scientist is to discover and understand that meaning. The aims of interpretive inquiry are understanding and description—a search for meaning with a focus on the process by which meanings are created, sustained, and modified. Denzin and Lincoln (2000) state that the constructivist/interpretive paradigm assumes there are multiple realities, and understandings are cocreated through interaction between investigator and respondents. Realities are understood as elusive mental conceptions that are socially based and dependent on the individual or group for their form and content (Guba & Lincoln, 1994).

Interpretive methodology assumes that reality is complex and context dependent, developed intra- and interpersonally, subjective rather than objective, and focused on

human experience (Monti & Tingen, 1999). Multiple ways of knowing are used to uncover the knowledge located within the human experience. For this reason, the interpretivist methodology compliments Kitwood's dialectical theory of AD and personhood, which posits that AD is a product of interpersonal processes and neurological impairment.

In this study, guided by the interpretivist approach and based on the assumption of symbolic interactionism that one can appreciate the experience of another only by understanding its construction by that individual, insights and meanings of the experience of wellness within illness were discovered. This understanding of the subjective experience of well-being acknowledges the ability of the person with AD to interpret experiences important to his or her life (Monti & Tingen, 1999).

Photo-elicitation

The use of photographs during an interview to encourage dialogue is known as *photo-elicitation*, first named in a paper published by researcher and photographer John Collier in 1957 (Harper, 2002). Photographs were first used as a method of data collection in anthropology, ethnographic research, and social science research to augment other research methodologies. Collier (1957) later expanded the role of photography in research by using pictures as an aid to the interview process and found the photographs served to jog memory, stimulate emotions, and help "the interview to proceed on its meaningful way" (p. 859). More recently, photographs have been used to look at social issues (Harper, 2002; Radley & Taylor, 2003). Erdner, Andersson, Magnusson, and Lutzen (2009) used photographs to study people with long-term mental illness, noting photography provides a bridge for those with cognitive limitations, offering a fuller

picture of the individual's world by supplying information that may not have been obtained through interview only.

The photographs used in photo-elicitation can be obtained from either the researcher or the participant. If taken by the study participant, the photographs produced are referred to as *reflexive photographs*, and the term *autodriving* is used to indicate that the interview is "driven" by the informants (Hurworth, 2003, p. 2). During the interview, the photos become the basis of the dialogue between the researcher and the study participant (Harrington & Lindy, 1999). This technique has been used in previous studies to look at a variety of issues, including social organization, community, identity, and cross-cultural issues (Harper, 2002).

When used as a research method, photography can be both communicative, in that it provokes and conveys meaning, and generative, because through discussions and analysis of the photographs new understandings may be created and deeper insight obtained (Close, 2007). Given the deficits associated with AD—including diminished attention, memory, and ability to communicate—multiple forms of data collection, including photography, may improve the individual's ability to reflect and dialogue.

The use of photos as a starting point for the interview is thought to enhance the potential for finding out the informants' views of life (Erdner et al., 2009). For those with AD, photo-elicitation provides participants a chance to speak for themselves and reduces the researcher's reliance on potentially culturally biased research instruments (Noland, 2006). Through the use of photo-elicitation with autodriving, and drawing on assumptions of symbolic interactionism, the person with AD is able to create

photographic evidence and symbolic representations of happiness that will allow others to see the world through their eyes (Close, 2007).

In this study, the person with AD and the caregiver were asked to take pictures representing situations and events that inhibit or support the experience of happiness. The pictures were then discussed during individual interviews. If a participant was unable to take pictures or meaningfully answer interview questions, he or she was excluded from the study. At the time of this study, I had found no previous research that utilized autodriving in a population of elders with mild to moderate AD. However, Hulko (2009) utilized photo-elicitation without autodriving as a method of data collection in her study exploring the subjective experience of mild to moderate AD. Using photographs taken by the researcher, Hulko found the pictures instrumental in the participant's articulation of his or her experience.

Study Design

Description of Sample

The participants in this study were referred by geriatricians and psychiatrists located in two communities in the northeast United States. For this study, the inclusion criteria were: English-speaking adults age 70 or older; living in the community with a family member or an identified caregiver; and diagnosed with mild to moderate AD by a geriatrician or psychiatrist at least 4 months prior to referral. The participants must be capable and willing to express themselves verbally and must score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study. The 10-item SPMSQ developed by Pfeiffer (1975) is widely used to evaluate orientation, memory, and concentration. The

scores on the observer-rated test range from 0 (normal) to 10 (severe AD), with test-retest reliability reported to be 0.8 and a sensitivity of 0.84 and specificity of 0.89 at a cut point of 3 or more errors (Cole, Dendukuri, McCusker, & Han, 2003).

In my study of 12 individuals with Alzheimer's disease, 5 participants were male and 7 were female with a mean age of 87 years 6 months (range 70 to 94). Eleven participants were White; 9 were originally from the United States, 1 from the United Kingdom, and 1 from Portugal. One participant was Black and from the United States. Five participants lived with their spouses. Seven lived in senior housing apartments, 2 lived in houses they owned, 1 lived in a home owned by children, and 2 participants lived in a nonsenior apartment. In terms of education, 2 participants had master's degrees, 4 had bachelor's degrees, 2 had attended secretarial school, 3 had completed high school, and 1 person completed the 10^{th} grade. The most common diagnosis was Alzheimer's disease, followed by depression (8 participants) and hypertension (5 participants).

To address Aim #2, each caregiver was invited to participate in this study. Inclusion criteria for the caregiver were English-speaking and willingness to participate. A total of 10 caregivers participated in the study.

Recruitment and Informed Consent

A letter was sent to psychiatrists and geriatricians listed in public records in two communities in northeast United States, requesting referrals to the study. These letters explained the purpose, the method, the subjects needed, and the inclusion criteria for this study. Seventeen persons with AD were referred and contacted; 12 met inclusion criteria. Five individuals were not accepted in the study: 1 was excluded because he lived outside the state, 1 was unable to communicate, and 3 scored too low on the SPMSQ.

Each participant was contacted by telephone after I received his or her contact information from the referring provider. During the initial phone call, the study was explained to the individual, who was then asked if he or she would be willing to participate in a study of happiness. An appointment was set for an initial in-person meeting at a time and place of the participant's choosing. Participants were given the choice of being screened for inclusion and informed consent in their home or at my office. All chose to be interviewed in their home.

Permission was also obtained from each participant to contact the family member or caregiver to explain the study and invite the caregiver to attend the initial meeting and participate in the study. All caregivers were invited to take part in this study. Caregivers and persons with AD were interviewed separately. Participation was completely voluntary, and participants were able to remove themselves from the study at any time, though none chose to do so. The informed consent form was constructed in accordance with the University of Utah Institutional Review Board (IRB), and all participants were consented prior to initiating interviews. As compensation for participation in the study, each participant was given a copy of the photographs.

Method of Data Collection

At the first meeting with the participant, the study was explained to both the person with AD and the caregiver. After obtaining consent, the SPMSQ was administered and demographic information about the person with AD was gathered, including age, gender, race, ethnicity, marital status, living arrangement, and co-occurring diagnoses.

A twelve-exposure disposable camera along with instructions on its use was given to the first 4 participants. At this time, two dates were chosen: one between seven and ten

days to pick up the camera for film development, and the next approximately four days after film pickup for the interview. Participants were reminded of the meetings by telephone.

The remaining 8 participants were accompanied by the researcher and invited to take pictures on a disposable camera, the researcher's digital camera or the person's own camera phone. The pictures were then downloaded onto my computer and printed out on a digital printer. The final meeting occurred within two to three days after taking the pictures.

To meet Aim #2, the caregiver was invited to join the study. If the caregiver was agreeable, consent was obtained, camera and instructions were given, and interview date and time was determined. Ten caregivers agreed to participate—5 spouses, 2 daughters, 2 sons, and 1 unrelated caregiver.

The data were collected through separate interviews of the person with AD and the caregiver. The interview involved photos taken by the interviewee as the starting point for discussion. The initial prompt was, *In what way does this picture represent happiness to you (or for the person with AD)?* From that point on, the discussion of the picture was led by the participant's narrative. Additional questions included: *How do you feel when you look at this picture? What is it about this picture that you wanted to share with me? I am interested in hearing what brings you happiness; was there anything you wanted to take a picture of but couldn't?* Wherever possible, the questions were adjusted to reflect the words of the subjects. Interviews were digitally recorded and professionally transcribed.

The data obtained from the interview may serve as a step toward the development of a new theoretical framework of happiness for persons with mild to moderate AD. This is consistent with symbolic interactionism (Hall & Callery, 2001). The length of time of the interview was between 60 and 90 minutes. After the interview, field notes were written immediately and included observations of nonverbal behavior and my overall impressions of the encounter. Recordings of the interview were electronically delivered to the transcription service.

Methods of Data Analysis

Interpretive Descriptive Analysis

Interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997) is an inductive analytic approach to qualitative research designed to create ways of understanding clinical phenomena. An alternative to traditional qualitative methodological approaches—such as grounded theory, phenomenology, and ethnography—interpretive description evolved as a distinct methodological approach designed to fit the kinds of complex experiential questions nurses and other applied health researchers might ask. Interpretive description acknowledges the constructed and contextual nature of human experience and at the same time allows for shared realities (Thorne et al., 1997).

The purpose of this study was to capture themes and patterns of happiness from subjective perceptions and generate an interpretive description capable of informing clinical understanding of happiness and well-being. Interpretive description provides a direction for the creation of an understanding of a phenomenon that is based on informed questioning, using techniques of reflective, critical examination, and that will ultimately

inform nursing (Thorne et al., 2004). The end result is a coherent conceptual description using thematic patterns and commonalities believed to characterize the phenomenon that is being studied while also accounting for individual variations within them—"Thus, the intended products of interpretive description would constitute not a new truth, but a sort of 'tentative truth claim' about what is common within a clinical phenomenon" (Thorne et al., 2004, p. 3).

Unlike phenomenology that asks the researcher to bracket assumptions (Schwandt, 2001), interpretive description presumes that there will be some theoretical knowledge and scientific basis in which human health and illness phenomena are located. This knowledge forms the basis for the preliminary "analytic framework" from which sampling, design, and early analytic decisions are made. As with all interpretive research processes, data collection and analysis inform one another iteratively, impacting the direction of the inquiry as new ideas arise (Thorne et al., 2004). An assortment of strategies within qualitative methodological literature exists to guide the analytic process.

Procedure of Analysis

It is unnecessary to separate the interpretation of narratives and the interpretation of the photographs, because they are both guided by interpretive methodology (Noland, 2006). Interviews were digitally recorded and electronically delivered to the transcription facility. Transcription of the interviews was done by an outside source, and I paid for the cost of transcription. The transcripts were read through for accuracy and to obtain a feel for the total content of the interviews, and meaningful segments and sentences were coded. The photographs were organized into general categories that emerged during the interviews as a way to understand the narratives using interpretive analysis. When all

interviews were completed and transcripts were coded, I interviewed 2 of the initial 4 participants a second time to review my categories and interpretations. They confirmed my initial groupings and analysis. Categories were further developed and grouped into themes. Thematic analysis of the data across transcripts was the final step in the analysis process (Corbin & Strauss, 2008).

To address Aim #2, a separate but identical process occurred with the data obtained from the caregivers. Caregiver transcripts were coded and compared to the themes discovered for the person with AD, looking for places of convergence and divergence related to the experience of happiness.

Coding

Coding, analysis, and transcription took place as interviews were completed in order to enable an increase in depth and efficacy, as well as to focus subsequent and follow-up interviews. Qualitative research is generally characterized by the simultaneous collection and analysis of data whereby both mutually shape each other (Sandelowski, 2000). The data were read closely and repeatedly and were coded line by line. Primary and secondary codes were identified and applied to each transcript, noting patterns of similarities and differences, then compared across cases for persons with AD. In this way, coded data were clustered into categories and then themes. A qualitative data management software package was utilized to summarize the data numerically with descriptive statistics to more completely describe the patterns or regularities of the data (Sandelowski, 2000) A reflexive journal was kept to record personal notes, including my values and beliefs, as well as for methodological decisions that were made to improve vigor (Charmaz, 1990; Corbin & Strauss, 2008).

To address Aim #2, the transcription, coding, and analysis of caregiver interviews was the same as for the person with AD. In addition to being coded across all caregiver interviews, themes identified by the caregiver were compared and contrasted to those developed from the data of the person with AD for whom they care, paying special attention similarities and differences.

Human Subjects Consideration

Human Subjects Approvals

Individuals with dementia, including AD, are considered to be vulnerable and were subjected to the University of Utah Institutional Review Board (IRB) rules of research on vulnerable populations. Guidelines from the University of Utah IRB informed the ethical conduct of this study to balance the individual's need for protection from exploitation during study participation with his or her right to participate in research. IRB approval from the University of Utah was obtained upon the successful defense of this proposal

Potential Risks

All studies in which data are collected represent a risk to privacy and confidentiality. Potential risks in this study were expected to be minimal, including fatigue and stress related to the personal disclosure that might occur during the interview. There was also a risk that taking photographs may put the participant in an uncomfortable or embarrassing situation. While the focus of data collection is not on sensitive data that would affect the insurability, employability, professional status, reputation, or integrity of the subjects, steps were taken to ensure adequate protections of privacy and

confidentiality of data and that participation was voluntary and free of any perception of coercion. Participants were instructed that they could withdraw at any time if the burden seemed too great.

Electronic transcripts and audio recordings were maintained on an encrypted thumb drive that was stored along with the paper transcripts, photographs, and negatives in a locked cabinet in my home office to which I alone hold the key. Audio recordings and transcripts were also maintained in security-encrypted, password-protected files on a password-protected computer in my home office for a period specified by the IRB.

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CHAPTER 4

PHOTO-ELICITATION AS A RESEARCH TOOL WITH PERSONS WITH ALZHEIMER'S DISEASE: ETHICAL DILEMMAS AND LESSONS LEARNED

Abstract

Recent research indicates that people with Alzheimer's disease (AD) can meaningfully report on their life. As a result, there is an increasing interest in finding ways to involve persons with AD in qualitative research to ensure their perspectives and experiences are included. Despite this, researchers have largely depended on interview or observation methods to inform their study, acknowledging concern regarding capacity for expressive language.

This article reports on the use of photography, specifically photo-elicitation with autodriving, in a qualitative study of happiness in persons with mild to moderate AD and explores the opportunities and challenges of using this methodology in this population. Results demonstrate that while photo-elicitation can be an effective tool for the researcher to use to understand the world of the individual with AD, it also presents practical challenges. Thoughtful application of this methodology can overcome these challenges, providing a richer level of understanding than interview alone can generate.

Introduction

The majority of the research currently available about Alzheimer's disease (AD) is derived from, and limited by, the medical model, which is focused on pathology, dysfunction, and the physical and biologic aspects of disease (Lyman, 1989). Consequently, AD is understood as a biomedical disorder caused primarily by neurodegenerative changes in the brain that result in marked progressive decline. As a result, persons with AD have been or are labeled as "victims" or "sufferers," believed to be unable to, or not wanting to, speak for themselves in a meaningful way (Bond, 1999). This belief, along with a paternalistic attitude that persons with AD would be harmed by their participation in research interviews, has resulted in the exclusion of their voices from research; instead, their voices are replaced with information and opinions provided by proxy caregivers (Beard, 2004). Research has thus predominantly focused on neurobiological factors of the disease and the impact of the disease on the caregiver, with little attention given to the impact on the person with AD (Cottrell & Schultz, 1993).

The biomedical view of AD has been challenged by Kitwood (1997), Sabat (2006), and others who suggest that a person's social environment and personal history may impact the expression and progression of AD symptoms. Kitwood (1997) advocates for person-centered approaches in AD care, emphasizing communication, relationship with others, and the viewpoint that the person with AD has personhood and rights, including the right for their experiences to be explored through research (McKeown, Clarke, Ingleton, & Repper, 2010). Cottrell and Schulz (1993) suggest the perspective of the person with AD should be sought in research, with AD patients taking the role of active participants and not simply subjects (Cottrell & Schultz, 1993).

The importance of the subjective experience of people with AD has been acknowledged, but how best to include their understanding is still being explored. Cognitive limitations, such as diminished memory and language impairment, may curtail access to narrative reports and minimize the usefulness of interviews. Nontraditional, out-of-the-box methodological strategies need to be considered in an effort to include the perspective of the individual, compensating for limitations while still respecting his or her right to participate in research and protecting the integrity of the research itself. One such example of a more inclusive methodology is the diary interview used by Bartlett (2012) to research the life of persons with AD. Bartlett modified and expanded the traditional diary interview method to allow participants to keep either a written, photo, or audio diary. This change allowed respondents to take an active role and have greater control in the research process.

The use of photography offers another method to explore the subjective experience of AD, as it allows persons with limited expressive language capacity to provide a visual image of their life. Through their selection of subject matter photographed, participants are able to control the information they share and the representation of their life and experience. This article builds on the work of Bartlett (2012) by describing the use of photo-elicitation, specifically the technique of autodriving (Harper, 2002) as a method to communicate thoughts and ideas through self-selected imagery in a qualitative study of positive emotion in persons with AD. The purpose of this article is to explore the opportunities and challenges in using photo-elicitation and autodriving with individuals diagnosed with mild to moderate Alzheimer's disease.

Photo-Elicitation

The use of photographs during an interview to encourage dialogue is known as *photo-elicitation*, first named in a paper published by researcher and photographer John Collier in 1957 (Harper, 2002). Photographs were first used as a method of data collection in anthropology, ethnographic research, and social science research to augment other research methodologies. Later, Bateson and Mead (1942) became the first to use pictures as the primary recording device in their research of the Balinese culture in the 1930s and 1940s (Jacknis, 1988). Collier (1957) later expanded the role of photography in research by using pictures as an aid to the interview process and found that photographs served to jog memory, stimulate emotions, and help "the interview to proceed on its meaningful way" (p. 859).

More recently, photographs have been used to look at social issues (Alexander, 2013; Harper, 2002; Radley & Taylor, 2003), to explore the experiences of children and adolescents (Mandleco, 2013) and to shed light on the subjective experience of mental illness (Sandu, Ives, Birchwood & Upthegrove, 2013). Erdner, Andersson, Magnusson, and Lutzen (2009) used photographs to study people with long-term mental illness, noting photography provides a bridge for those with cognitive limitations, offering a fuller picture of the individual's world by supplying information that may not have been obtained through interview only.

The term *photo-elicitation* is used when photographs serve as the basis of an in-depth interview. Photographs can be created by the researcher or participant, the latter being a more inductive approach known as *autodriving* to indicate that the interview is

guided or "driven" by examination of the participant's own photographs (Hurworth, 2003).

I report here on the use of photo-elicitation with autodriving as a method of data collection in a qualitative study of positive emotion in a sample of 12 persons with mild to moderate AD. Participants were asked to take pictures representing situations and events that either inhibit or support the experience of happiness. The pictures were then used as the starting point for an in-depth semistructured interview. The reason for using photo-elicitation with autodriving in this study of happiness in mild to moderate AD is both theoretical and methodological. In this study, I chose the interpretive theoretical approach of symbolic interactionism to frame my work, including the assumption that meaning is coconstructed through a social process that draws on culturally transmitted symbols. Meaning is therefore a product of our engagement with the world and reflects the understanding of the experiences of the individual in interaction with the world and others (Blumer, 1969). Symbolic interactionism suggests the researcher must interact with a person to understand the research topic within the context of the individual's life.

In this study, photographs obtained through autodriving allow me to "see" the experience of happiness as the participant sees it and to connect happiness contextually to the individual's social world. Consistent with symbolic interactionism, the photographs produced through autodriving are not regarded as an objective representation of reality or truth. Rather, the full meaning of the image is cocreated rather than just subjective, and is context dependent—in other words, developed through the individual's interaction with others. In photo-elicitation interviews, the subject shares the full contextual meaning of the photos rather than solely reflecting internal values (Harrington & Lindy, 1999).

As a research method, photography can be both communicative (because it incites and conveys meaning) and generative (because new understandings may be created and deeper insight obtained through discussions and analysis of the photographs; Close, 2007). Photographs can serve as memory triggers in this population of persons who are frequently impacted by memory impairment. Also, given the cognitive deficits associated with AD, the use of multiple forms of data collection, including photographs, may improve the individual's ability to reflect and dialogue and allow others to see the world through his or her eyes (Close, 2007).

At the time of this study, no previous research was found utilizing photo-elicitation with autodriving in persons with dementia. Hulko (2009) utilized photo-elicitation *without* autodriving in a study exploring the subjective experience of mild to moderate AD. However, I believe photo-elicitation with autodriving is an appropriate data collection method for this study of happiness in mild to moderate AD because it provides a way to build rapport while supplying a visual representation of things that matter to the participant's experience of happiness. In what follows, I report on the benefits and challenges of using photo-elicitation and autodriving with individuals diagnosed with mild to moderate Alzheimer's disease.

Context of Current Research

The worldwide estimate of people living with AD in 2010 was 35.5 million. This number is expected to grow to 65.7 million by 2030 and to 115.4 million by 2050 (Alzheimer's Disease International, 2012). Add to this the number of caregivers and family members who are also affected by the disease, and the number of people directly and indirectly impacted by AD is staggering.

Each individual living with AD confronts uncertainties about his or her future health and prognosis. In severe AD, disturbances in cognitive and behavioral functioning may significantly limit an individual's ability to function independently. But in mild AD, the individual may struggle with memory loss but still remain able to communicate and participate meaningfully in a social context as well as in some personal care and daily living activities. In general, people with AD and other dementias have high rates of psychiatric symptoms, including depression, when compared with people who have normal cognitive function (Alzheimer's Disease International, 2012).

A growing body of research has emerged that is focused on the lived experience of AD and the impact of these experiences on personhood, quality of life, and well-being. Studies suggest a connection between happiness and well-being to increased social engagement, an important link given social inclusion is a precondition of our perceptions of personhood (Knapp et al., 2006; Mendes de Leon, Glass, & Berkman, 2003; Nolan, Ryan, Enderby, & Reid, 2002).

Maintaining optimal physical and emotional health is an important treatment goal in an effort to reduce disability and suffering and improve quality of life. Yet many studies broadly described as exploring the subjective experience of AD focus on the deficits and social stigmatization that may accompany the disease, rather than a subjective sense of—or capacity for—well-being. Both quantitative and qualitative studies report on positive affect as objectified and measured on various quality of life tools (Brod et al., 1999; Cahill et al., 2004; Katsuno, 2005; Logsdon & Albert, 1999). In doing so, positive affect may be separated from the contextualized experience of the subject. Quality of life tools may therefore produce information concerning the amount of

measured attributes but limited insights regarding the qualities themselves. Finally, few report the subjective meaning or perception of happiness. As a result, the perspective of the person with AD is frequently overlooked, leaving one to wonder if conventional quality of life and outcome measures are significant, or even relevant, to the population being assessed.

Current research in this area, though sparse, suggests the importance of continued exploration into the relevance of positive emotion for optimal health (Linley, Joseph, Harrington, & Wood, 2006). Positive emotions, such as happiness, indicate a person's inner optimal well-being while also motivating engagement with the surrounding community and environment. This is especially significant in light of research suggesting an association between cognitive stimulation and AD (Danner, Snowdon, & Friesen, 2001; Wilson et al., 2002).

The aim of my qualitative study was to unpack the concept of happiness with regard to factors that promote resilience, the role of positive experiences, and the effects of positive relationships. To this end, photo-elicitation was used to explore the phenomenon of happiness from the internal perspective of an individual with AD. The purpose of this paper is to explore the opportunities and challenges in using photo-elicitation and autodriving with individuals diagnosed with mild to moderate Alzheimer's disease.

Research Design

This was a qualitative study involving semistructured interviews and photos obtained through photo-elicitation. Transcripts of interviews were analyzed using

interpretive design to develop shared themes of the key elements of each participant's experience of happiness.

Participants

Participants were recruited by referrals from geriatricians in two communities in the northeast United States in accordance with the University of Utah Institutional Review Board guidelines. A letter describing the study and inclusion criteria and requesting referrals to the study was sent to geriatricians listed in public records and professional organizations in these two communities. The inclusion criteria for the participating individuals with AD were: English-speaking adults age 70 or older, living in the community with a family member or an identified caregiver, and diagnosed with mild to moderate AD by a geriatrician at least four months prior to referral. To be accepted to the study, participants must be capable and willing to express themselves verbally and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study.

The 10-item SPMSQ developed by Pfeiffer (1975) is widely used to evaluate orientation, memory, and concentration. The scores on the observer-rated test range from 0 (normal) to 10 (severe AD), with test-retest reliability reported to be 0.8 and a sensitivity of 0.84 and specificity of 0.89 at a cut point of three or more errors (Cole, Dendukuri, McCusker, & Han, 2003).

Seventeen individuals with AD were referred to this study, 12 of whom met inclusion criteria and participated in the research. Five were male and 7 were female, with a mean age of 87 years 6 months (range 70 to 94). Eleven participants were White, with 9 originating from the United States, 1 from the United Kingdom, and 1 from

Portugal. One participant was Black and from the United States. Five participants lived with their spouses. Seven lived in senior housing apartments, 2 lived in houses they owned, 1 lived in a home owned by children, and 2 participants lived in a nonsenior apartment. In terms of education, 2 participants had master's degrees, 4 had bachelor's degrees, 2 had attended secretarial school, 3 had completed high school, and 1 had completed the 10th grade. The most common diagnosis was Alzheimer's disease followed by depression (8 participants) and hypertension (5 participants). Of the 5 individuals not accepted in the study, 1 was excluded because he lived outside the state, 1 was unable to communicate, and 3 scored less than 3 on the SPMSQ.

All caregivers were invited to participate in the study. Of the 10 caregivers who agreed to participate, 5 were spouses, 2 were daughters, 2 were sons, and 1 was an unrelated caregiver. Two participants were widows whose caregivers felt they had not worked with the individual long enough to accurately judge sources of happiness and therefore chose not to participate in the study.

Procedure

Each participant was contacted by telephone after receiving his or her contact information from the referring provider. During the initial phone call, the study was explained to the individual, who was then asked if he or she would be willing to participate in a study of happiness. An appointment was set for an initial in-person meeting at that time. Permission was also obtained from the participant to contact the family member or caregiver to explain the study and invite him or her to attend the initial meeting and participate in the study.

At the first meeting, the study was again explained. Each participant was asked questions to ensure his or her understanding of the study. Consent was obtained from all participants and a release to reprint photographs was signed by all participants. The SPMSQ was administered to all persons with AD at the initial meeting. The first 4 participants were given a twelve-exposure camera for approximately one week and asked to take pictures representing situations that inhibit or support the experience of happiness. Each person with AD was accompanied by his or her caregiver to assist with logistical concerns such as transportation or difficulty with the camera. Two additional meeting dates and times were established—the first in seven to ten days to pick up the cameras for film development, and a final meeting was set for the interview approximately four days after film pickup. For these 4 participants, the final interview occurred approximately 10 to 14 days after the cameras were first distributed.

The last 8 participants were contacted and consented in the same fashion as the initial 4 individuals. However, the final 8 participants were accompanied by me rather than a caregiver when taking the pictures. At the first meeting, a date and time was set to take pictures within three days. The individuals took pictures using either a disposable camera, my digital camera or their camera phone. The pictures were then downloaded onto my computer and printed out on a digital printer. The final meeting occurred within two to three days after the pictures were taken.

With this process, I met with each of the 12 participants three times during the study—once to explain the study and obtain consent, a second time to either retrieve film from the first 4 participants or to take photographs with the final 8 participants, and the final time for the interview. All 12 participants and the participating caregivers were

instructed to take pictures representing happiness from the perspective of the person with AD. The photographs were then used as a catalyst for discussion at the final meeting.

Semistructured, open-ended questions were used in the interview. All participants, including caregivers, were able to take photos and answer questions. The photographs were placed on a table one at a time, and the person who took the pictures was invited to tell me about each picture and explain how the picture represented happiness. With each picture, I asked the person with AD the initial question, *In what way does this picture represent happiness to you?* From that point on, the discussion of the picture was led by the participant's narrative. The 10 caregivers who participated in the study were interviewed separately but in a similar fashion, their first question being, *In what way do you believe this picture represents happiness for the person with AD?* At the conclusion of the interview, field notes documenting my observations—including descriptions of the setting, nonverbal behavior of the participants, and my overall impressions—were written. Personal notes were kept in a reflexive journal. Photographs were numbered to correspond to the taped interview.

Data Analysis

Interviews were digitally recorded and professionally transcribed. Interviews were transcribed, coded, and analyzed as completed, staying close to the data. Transcripts were read and re-read several times to ensure accuracy and to increase familiarity with the data. In vivo codes were initially applied to the transcripts to preserve the participants wording of their ideas and meanings. In vivo codes were included in the comparative analysis process. The next coding phase was line-by line coding, which allowed me to identify concepts and processes, and to see the nuances within the data. These codes

were subjected to the same comparative and analytic treatment as the in vivo coding. Using NVivo software to analyze the codes, I identified categories which came directly from the data. Focused codes then were developed through the comparative process applied to the identified categories which led to the development of themes. Themes were identified and coded for each transcript. Once all individual transcripts had been coded, repeating patterns of similarities and differences were identified over all the transcripts and discussed with a colleague who is experienced in qualitative analysis and familiar with the study and data. Concepts and categories were coded and compared within and across cases and were clustered using NVivo software. Memos that summarized relevant information for each participant were maintained throughout the research process.

All activities conducted during this study were reviewed and approved by the Institutional Review Board of the University of Utah. The names of all participants have been changed to safeguard confidentiality.

Methodological Challenges

This study demonstrated that photo-elicitation can be an effective tool in understanding the world of the individual with AD, but it also presents practical challenges. In this section, I report the challenges posed by shifting memories, language, the need for reflexivity, and the role of the researcher-clinician.

Challenge of Data Collection:

Shifting Memories

Data collection occurred over a total of seven months. The process was reviewed after the initial four interviews were completed, a process that revealed several challenges

necessitating changes to the methodology. First, during the interview, which occurred approximately one week after participants received the camera, all 4 persons with AD had difficulty remembering both the experience of taking the picture and the rationale for its selection. For example, granddaughter Rachel accompanied participant Laura during picture-taking and recorded Laura's reasons for each photo. For three of the nine pictures taken by Laura, Rachel's recorded notes reported meanings very different than those expressed by Laura during the interview six days later. The inability of these 4 participants to remember the photographs is not surprising given that Alzheimer's disease is a complex neurological disease with multiple symptoms, including memory impairment (Blazer & Steffens, 2009).

While memory impairment is a well-documented and prominent feature of AD, it is progressive in nature; Cottrell and Schulz (1993) report that memory deficits are not necessarily a barrier to experiencing the "here and now." The individual may still accurately report the experiences of the present time although be unable to report past experiences. Memory impairment is less problematic in this study as the focus is on the coconstruction of the experience rather than treating the photo as a representation of objective truth.

The distinction between the *memory* of happiness and the *experience* of happiness is important to the study and therefore important to review. Reporting current emotions is relatively straightforward. Remembering and evaluating past events is more difficult, requiring introspection, the ability to retrieve past emotions, and the ability to integrate experiences that may have occurred over many moments to determine a response that represents the "average" of the moments (Kahneman & Riis, 2005). Daniel Kahneman

and Jason Riis (2005) describe an individual's life as a series of moments, each of which last up to three seconds and then disappears, but some of which can be retrieved at a later time. They use the term the *experiencing self* to signify the individual's appraisal of a moment as it is happening and the *remembering self* to indicate a retrospective viewpoint.

The remembering self may not accurately represent the actual experience for all individuals with or without AD. Fredrickson and Kahneman (1993) reported that when asked to judge a past event, the person creates a representative moment of the experience through averaging the affect experienced during the most extreme moment (peak) and the affect experienced near the end, a process referred to as the Peak-End rule. Kahneman (2000) suggests that the duration of either positive or negative affect has minimal effect on the memory of the experience. It is this representative moment created using the Peak-End rule, with disregard for the duration that provides the "snapshot" used to evaluate past experiences. But does that snapshot represent the actual experience? In a study by Kahneman, Fredrickson, Schreiber, and Redelmeier (1993), participants immersed one hand in painfully cold water twice. One trial lasted 60 seconds, with water temperature at 14° C. The other trial lasted 90 seconds, with water temperature at 14° C for the first 60 seconds and then gradually increased to 15° C during the final 30 seconds. The participants were later given a choice to repeat either trial. A significant majority of subjects chose to repeat the longer trial. Although counter-intuitive, this supports the Peak-End rule, which suggests that adding a period of reduced discomfort to a more unpleasant episode will result in a more favorable evaluation of the episode. While the choice of extending pain appears illogical, it is explained by the concept of duration

neglect, indicating that duration of the positive or negative event has little effect on the memory (Fredrickson & Kahneman, 1993).

The work of Kahneman and others highlights the difficulty in using retrospective evaluations of individuals to assess an experience, irrespective of the presence of a brain disease such as AD. This suggests that our approaches to studying happiness should be revised to focus on the present—on the experiencing self. This would also be more in line with the physiological and experiential nature of AD. For this reason, the questions posed in this study were asked in the present tense (What makes you happy *now?)*. It is also the reason I accompanied the final 8 participants as they took the photographs, offering each participant the use of my digital camera or a disposable camera while documenting the thoughts and reasons behind the picture selected. Use of a digital camera enabled me to print the photographs more quickly than conventional development allowed. I believe this change may have allowed some participants to more easily remember their reason for photo selection. However, the photographs were not used as representation of objective truth but rather as a springboard for dialogue. Through discourse, the experience of happiness was cocreated by the researcher and participant, as occurs when pictures supplied by the researcher are used during the interview. I consider the findings drawn from the first four interviews to be as valid as the findings drawn from the final eight interviews. This belief was supported in follow-up interviews with 2 of the initial 4 participants in which my categories and interpretations were confirmed as reflections of their ideas.

Challenge of Data Collection: The Language of Alzheimer's Disease

The second challenge of data collection involved the language used to refer to AD symptoms. Each participant was diagnosed with AD by a geriatrician. Each caregiver was aware of the diagnosis; all 12 participants had been told of their diagnosis in the past, but 6 caregivers said they were uncertain that the participant remembered the diagnosis. Of the 12 participants, in fact, 6 were aware of the diagnosis and used the term *dementia* during their interview. For the other 6 participants, caregivers asked that the term *memory loss* or *memory impairment* be used during the interview rather than the word *dementia*. I believe that the caregiver's request to not use the terms *dementia* or *Alzheimer's* reflects a paternalistic conviction that doing so protects the care recipient from emotional distress.

I do not believe that the inconsistent use of the word *dementia* takes away from the usefulness of findings obtained from this study. Participants were chosen based on the inclusion criteria for this study, criteria that included having a diagnosis of mild to moderate Alzheimer's disease and the ability to describe and reflect on the experience of happiness. The participants provided different perspectives about the experience, deepening the understanding of happiness by identifying essential shared aspects and differences that appear across the participants. It is my belief that conducting this study using the language of the participant supports the personhood of each individual and is inherently less pathologizing for people with AD while addressing the aim of the study.

Challenge of Self Report: Reflexivity

A third challenge of data collection became obvious when I started to accompany each person for picture-taking. Photographs were used in this study as a method of

gaining access to the interpretation of happiness by a person with AD. However, when participants were asked to identify an item or subject they could photograph that represented happiness, some individuals asked me for suggestions. The reason for this may have been difficulty in abstract thought, self-doubt, fear of making a mistake, or desire to please me. Symbolic interaction, the interpretive theoretical approach used to frame my work, assumes that meaning is coconstructed through a social process. Therefore, the presence and input from anyone assisting the individual will be represented in the picture taken. Moreover, how people come to value certain things and what symbolizes or represents that value is also formed through social processes. Kitwood (1997) underscores the influence of the social environment by reporting that interaction with the "other" not only affects quality of life, but also affects the expression and progression of Alzheimer's disease.

The photographs and the ensuing interviews provide a valuable source of data in qualitative research. The tenets of symbolic interactionism recognize both as co-constructions of the researcher and the participant, the implication for this method being the acknowledgment of both the inability to remove and the need to understand the influence of the person assisting with the picture-taking. It would also be reasonable to extrapolate this insight to how researchers and clinicians view the information obtained from the caregivers who serve as proxy reporters for, or interpreters of, the subjective experiences of people with AD.

To address this challenge, I kept a reflexive journal throughout the research process. When accompanying the final 8 participants, I paid special attention to my influence on the photograph taken by maintaining a self-reflexive consciousness. I

documented both the stated reason for choosing the picture subject and the selection process itself. Instead of offering suggestions when solicited, I encouraged a slower pace that several times led to reflection by the participant; this also played a role in the co-construction of the photograph.

From the symbolic interaction perspective, it is impossible to eliminate social influences from the picture. Instead, it offers a way to connect the person's experience back to the social context, linking his or her personal values with social context in a way that is missing from other theories and methods.

Challenge to Researcher-Clinician: Shifting Roles and Perspectives

A fourth and significant challenge for me during this research was negotiating my dual role—that is, my professional role as clinician and my role as researcher. As a geriatric-psychiatric mental health nurse practitioner, I counsel and treat clients with AD and their families. As a researcher, my role is that of an impartial observer and recorder. None of the research subjects were my clients, and no interviews occurred in my clinical office. Still, the interview might be perceived as therapeutic given the one-on-one attention, the personal nature of the topic, and the interpersonal skills that are part of my training and practice and that may have carried over into the interview. Garland, McCabe, and Yeh (2008) report that this phenomenon can also occur with trained interviewers who are selected for their interpersonal skills. Hellstrom, Nolan, Lennart, and Lundh (2007) suggest that establishing good relationships may be especially important in research involving people with AD; they suggest that time should be spent building rapport, trust,

warmth, and empathy. These factors may influence the participants' understanding of the interview as therapeutic irrespective of any study explanation provided.

Not only can the shift in orientation from clinician to researcher impact the participant, it led to some internal role confusion for me. Yanos and Ziedonis (2006) adeptly describe this role confusion as a "clash between the clinical mandate to act in the patient's best interest (beneficence) and the scientific mandate to pursue truth with all appropriate rigor (scientific autonomy)" (p. 251). Being positioned at the intersection of research and clinical practice is both exciting, in that it can result in the development of clinically relevant research, and concerning, because of possible ethical and role conflicts.

There are several benefits of this dual role. At the most fundamental level, a clinician possesses an understanding of the mental health-care system based on experience in that system and can therefore provide insights into the "real-world" experience for staff and clients. Serving as a bridge between theoretical knowledge and practical application can lead to clinically relevant research and the development of evidence-based treatments. Yanos and Ziedonis (2006) suggest the clinician-researcher can facilitate the dissemination and implementation of evidence-based treatments into routine clinical practice by communicating their importance in terms understood and valued by staff and administrators and by developing strategies to incorporate empirically validated treatments into clinical settings.

There are several ethical considerations of the clinician-researcher role, many of which did not occur during this research. One I did experience was the dissonance between my desire to act in the individual's best interest in a clinical sense along with the

research directive to remain neutral so as to understand the experience of the individual without the distraction of my own thoughts and beliefs. An example of this dilemma was the experience of straddling the line between exploring a person's coping strategies and responding to the person's coping strategies by either supporting or suggesting new coping skills. I found it difficult to hear participant Mildred share her feeling of sadness and not be able to respond with suggestions of coping strategies to alleviate her unhappiness.

To address role conflict, Yanos and Ziedonis (2006) advocate the development of an integrated clinical and research identity to balance the responsibilities of researcher and clinician. Yanos and Ziedonis (2006) suggest that to do so requires introspection, examination of the moral principles that guide one's practice, and an understanding of the importance of research and clinical practice in meeting that principle. I found incorporating these themes into my personal reflexive journal to be very helpful; in fact, it made it easier for me to maintain a more objective stance with the participants.

Using Photo-Elicitation and Autodriving Techniques with Persons with Alzheimer's Disease: Lessons Learned

Multiple lessons were learned during the seven months of data collection in this population of individuals with mild to moderate Alzheimer's disease. First, Alzheimer's disease is a heterogenous disease with many different presentations and different levels of cognitive and memory impairment. I found it better to assume that memory impairment was a significant part of the illness for all participants regardless of how they presented initially. Assuming considerable memory impairment, I communicated multiple times

with each participant via telephone. At each meeting, I left reminder notes indicating the date, time, and place of our next meeting, and I always confirmed the appointment with a phone call the day before. During the initial phone contact, I learned from each caregiver if the individual with AD knew of his or her diagnosis and adjusted my language accordingly. I also wrote detailed notes in large font to explain the study and the use of the camera.

No more than three days separated the day of picture-taking from the day of interview for the last 8 participants. I accompanied all individuals with AD as they took pictures, cognizant of the impact of my words and actions on their choice of subject matter. I offered each person a disposable camera or the use of my digital camera. I allotted two hours for each interview and photo session to allow time for me to restate the purpose of the study and any previous events, to permit time for the participant to become comfortable with me, and to allow for the conversation to develop at a pace determined by the participant.

I took my reflexive journal with me on all visits with study participants. After leaving each appointment, I sought out a quiet place to sit and write down my thoughts and impressions. Entries written after picture-taking many times led me to questions or insights that I subsequently addressed during the interview.

Advantages of Photo-Elicitation and Autodriving Techniques with Persons with Alzheimer's Disease

The use of photo-elicitation with autodriving in persons with AD presents some practical challenges but also offers some advantages. First, this methodology provides a concrete representation of an abstract concept—in this case happiness—thus allowing me to see what could not be communicated with words. The photos serve as the basis of a conversation from which the researcher can extrapolate an understanding of the experience that can then be confirmed through discourse. At the same time, the photographs and the ensuing dialogue provide the participant an opportunity to reflect on the experience and therefore reflect on his or her life, resulting in the development of meaning and insight for both the researcher and the participant.

This methodology appeared to offer benefits to the participants as well. The inclusion and active engagement of the participants in picture-taking made them partners in the research process. The ability of the individual to control his or her photographs supported the personhood of the individual by providing an opportunity for the expression of self, the loss of which has been linked to the appearance and progression of AD symptoms (Kitwood, 1997).

The findings of this study suggest that happiness is associated with living a life that supports the individual's core values. Happiness was found to be historically and contextually based, socially constructed, and not just grounded on cognition. Values were not universal, but could be understood for each person by spending time with him or her to draw out those values. This suggests the only way to obtain a contextualized

understanding of happiness and other values, such as personhood, in AD is to spend time with the person and to deconstruct the experience through discourse to better understand the contexts upon which it is based. Photo-elicitation with autodriving provides a methodology that is present-focused, subjective, and coconstructive. As such, it may have implications for the assessment and development of interventions to improve quality of life in this population.

Conclusion

Alzheimer's disease is a debilitating neurological disease that affects cognition, including impairment of memory and language skills. Data required to study the lived experience in AD is culled from the expression of the experiences from the personal lives of individuals with the disease. Unfortunately, cognitive impairment can limit the ability for individuals with AD to express their thoughts and feelings through conventional dialogue. Photo-elicitation can provide an additional tool for the researcher to use to enter into the world of the individual with AD to better understand the lived experience of AD. It is not without challenges, but with thoughtful application of this methodology these challenges can be overcome, supplying a richer level of understanding than can be generated by interview alone.

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CHAPTER 5

WELLNESS WITHIN ILLNESS: HAPPINESS IN PERSON WITH ALZHEIMER'S DISEASE

Abstract

It is generally understood that happiness and quality of life are important goals of dementia care. Reports obtained from staff and family caregivers have historically been used to measure positive affect as a component of quality of life. However, proxy reports have been shown to differ from appraisals obtained by the person with Alzheimer's disease. As a result, it is widely believed that whenever possible, evaluation should be obtained from the individual's own perspective.

Little is known of the subjective experience of happiness in persons with mild to moderate Alzheimer's disease. This article reports on a qualitative study of happiness in a sample of 12 persons with mild to moderate Alzheimer's disease using photo-elicitation and individual interviews for data collection. Results demonstrate that people with mild to moderate Alzheimer's disease can provide meaningful evaluations of quality of life, and that lifelong values continue to be important in the presence of Alzheimer's disease. Values were found to be historically and contextually based and constructed in relationship to other people. Therefore, the only way to obtain a contextualized understanding of happiness and other values in Alzheimer's disease is to spend time with the person in constructive discourse and interaction.

Introduction

The majority of the information currently available about Alzheimer's disease (AD) is derived from, and structured by, research based on a medical model focused on pathology, dysfunction, and the physical and biologic aspects of disease (Lyman, 1989). As a result, AD is predominantly understood as a biomedical disorder caused by neurodegenerative changes in the brain that result in marked progressive decline.

This strictly biomedical view has been challenged by Kitwood (1997), Sabat (2006), and others who suggest that a person's social environment and personal history may impact the expression and progression of AD symptoms. Kitwood (1997) claimed that personhood—defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being [which] implies recognition, respect and trust" (p. 8)—can be undermined or supported by social exchanges with others. Conspicuously absent from Kitwood's conceptualization of personhood is cognitive ability, a component included in earlier definitions of humanhood (Fletcher, 1974). Cognitive loss has traditionally been associated with diminished personhood (Harrison, 1993; O'Connor et al., 2007). Kitwood's intentional omission of cognition in his theory of personhood allows for a broader vision of personhood that can be applied to those with cognitive impairment as seen in Alzheimer's disease.

A further challenge to the biomedical model has come from the field of positive psychology, which aims to shift psychiatry's focus from pathology to include an individual's strengths, including positive emotion (Seligman, 1999). Studies suggest the benefits of happiness and well-being include increased social engagement, understood to be a precondition of personhood (Diener, Kesebir & Tov, 2009; Knapp et al., 2006;

Mendes de Leon, Glass, & Berkman, 2003; Nolan, Ryan, Enderby, & Reid, 2002). Social engagement has also been associated with a reduced risk of cognitive decline and dementia. As such, positive psychology offers a novel perspective that could be applied to AD both as a way to support personhood and to protect against cognitive decline.

Maintaining optimal physical and emotional health is an important treatment goal in an effort to reduce disability and suffering and improve quality of life. Quantitative and qualitative studies measure positive affect on various quality of life tools that utilize inconsistent constructs chosen by the researcher with such terms as *well-being*, *positive affect*, and *happiness* used interchangeably and without clear definitions (Brod, Stewart, Sands, & Walton, 1999; Katsuno, 2005; Logsdon, Gibbons, McCurry, & Teri, 1999; Rabins, Kasper, Kleinman, Black, & Patrick, 1999; Ready, Ott, Grace, & Fernandez, 2002). On these tools, positive affect is often a sign read by others, not a subjective measure. It is difficult to imagine that a construct without definition or conceptual agreement can be accurately captured in a measurement tool.

Still, inclusion of a positive affect domain is important, as research suggests a connection between positive emotion, happiness, and well-being and the benefits in physical health, emotional health, and cognitive stimulation that may improve cognitive abilities (Diener, Kesebir & Tov, 2009; Knapp et al., 2006; Mendes de Leon et al., 2003). Little research to date has focused solely on the subjective (emic) experience of happiness, and it is unclear if affect adequately represents the construct of happiness or subjective well-being. Despite research suggesting that persons with AD can meaningfully comment on their life, much of the current knowledge of positive emotion comes from studies utilizing information obtained from the proxy caregiver (Logsdon et al., 1999; Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996; Perales, Cosco, Stephan,

Haro & Brayne, 2013). As a result, the perspective of the person with AD is frequently overlooked, leaving one to wonder if conventional quality-of-life and outcome measures are the best assessment of the population being assessed.

Study Purpose

While many quantitative and qualitative studies report on positive affect as measured on various quality-of-life tools, few report on the subjective meaning of happiness (Cahill et al., 2004; Dröes et al., 2006; Katsuno, 2005). Research has tended to reduce happiness and well-being to a single measure of affect or mood, thereby minimizing the usefulness of research results and calling construct validity and applicability to intervention into question.

The purpose of this study was to explore the emic experience of happiness in individuals with mild to moderate Alzheimer's disease from the perspective of the science of positive psychology, which aims to build on strengths rather than focus on loss. Identifying the presence of happiness in persons with AD challenges the prevailing social paradigm that views AD as a "burden" and "worse than death" and the individual with AD as "defective" (Patrick, Starks, Cain, Uhlmann, & Pearlman, 1994). These beliefs contribute to the restricted social roles, stigma, and diminished personhood associated with AD.

This study draws on the insights of positive psychology to investigate the capacity and existence of a subjective sense of happiness and well-being from the perspective of the person with AD in an attempt to gain a more nuanced and multifaceted understanding of the experience of happiness and well-being in this group. A more complete

understanding of these experiences may open up the possibility to change the narrative from one of loss to one of adaptation and strength.

The specific aims of this study are: (1) to describe the subjective understanding and perception of happiness in individuals with mild to moderate AD and (2) to compare and contrast what people with AD consider important to their happiness with what the caregiver believes is important for their happiness. This article reports on findings related to the subjective understanding and perception of happiness for individuals with AD based on data collected through photo-elicitation and interview procedures.

Impact of Alzheimer's Disease

The 2010 estimate of people living with AD worldwide was 35.5 million. This number is expected to grow to 65.7 million by 2030 and to 115.4 million by 2050 (Alzheimer's Disease International, 2012). Add to this the number of caregivers and family members who are also affected by the disease, and the number of people directly and indirectly impacted by Alzheimer's disease is staggering.

Evidence suggests that AD is an evolving process that starts years before the onset of clinical symptoms and that follows a predictable pattern of progression in the brain (DuBois et al., 2007). Jack et al. (2010) identify three clinical phases of AD associated with increasing impairment that can be affected by several factors, including comorbidities and cognitive reserve. Although an individual's ability to function independently is significantly limited in severe AD, in mild AD the individual may struggle with memory loss but still be able to communicate and participate meaningfully in a social context as well as in some activities of personal care and daily living.

The dominant disease model in the United States is the biomedical model, which assumes disease is found in biochemical processes exclusive of social, psychological, and behavioral dimensions of the illness; such a model positions the person with AD as a patient (Engel, 1977). In contrast, Kitwood believed each event experienced by a person with AD has both a psychological and biological component, and the interplay between these two factors and the social environment creates the dementia-associated symptoms that constitute threats to one's personhood (1990). According to Kitwood, the negative interactions of others contribute to the loss of personhood in people with AD.

Correlates of Well-Being: Connecting Well-being to Mental and Physical Health

The core hypothesis of positive health and well-being has been identified as the contribution of well-being to the maintenance or restoration of mental and physical health and physical functioning of an individual (Ryff, Singer, & Love, 2004). Although the measured constructs of well-being and positive emotion vary between studies, evidence does exist to suggest an association between well-being and positive emotion on the one hand and mental health, physical health, psychosocial health, and resilience on the other.

Recent research findings suggest an association between well-being and physical health, including neuroendocrine, immune, cardiovascular, and sleep correlates (Chida & Steptoe, 2008; Davidson, Mostofsky, & Whang, 2010; Ostir, Berges, Markides, & Ottenbacher, 2006; Pinquart, 2001; Ryff et al., 2004; Steptoe, Wardle, & Marmot, 2005). Specifically, multiple studies have suggested an association between positive emotions and improved biological markers, including heart rate, blood pressure, inflammatory and coagulation factors, lower total cholesterol/HDL cholesterol ratios, lower weights, lower

glycosylated hemoglobin levels, and lower cortisol levels (Chida & Steptoe, 2008; Davidson et al., 2010; Ostir et al., 2006; Ryff et al., 2004; Steptoe et al., 2005).

Well-being and positive emotion have also been associated with psychosocial factors such as spirituality, greater social connectedness, larger social support network, and lifestyle factors—all of which may lead to cognitive stimulation and could in turn improve cognitive ability, delay onset of impairment, and increase longevity (Chan & Lee, 2006; Danner, Snowdon, & Friesen, 2001; Diener, Kesebir, & Tov, 2009; Knapp et al., 2006; Mendes de Leon et al., 2003; Snowdon, 1997; Snowdon et al., 1996; Steptoe et al., 2009). Lifestyle factors—including cognitive, physical, and social activity—have been suggested to have a beneficial effect on cognitive function and a protective effect against dementia, possibly delaying the onset of impairment (Fratiglioni, Paillard-Borg, & Winblad, 2004; O'Connor & Draft, 2013). Therefore, an approach to conceptualizing, researching, and caring for individuals with AD that incorporates a more holistic view of health and well-being is an important step toward the development of interventions aimed at easing emotional and physical suffering and at potentially reducing healthcare costs.

Methodology

Design and Participants

This research was a qualitative interpretive study involving semistructured interviews and photo-elicitation methods of data collection. Transcripts of the interviews were inductively coded and analyzed through a process of constant comparative analysis among subject responses to develop shared themes of the key elements of the participants' experience of happiness. Transcription, coding and analysis took place as interviews were completed to enable an increase in depth as well as to focus subsequent

and follow-up interviews. All activities which were conducted throughout this study were reviewed and approved by the Institutional Review Board of the University of Utah. The names and initials of all participants have been changed to safeguard confidentiality

A letter requesting referrals to the study and describing the study and inclusion criteria was sent to geriatricians and psychiatrists listed in public records and professional organizations in two communities in northeast United States. Inclusion criteria were: English-speaking adults age 70 or older; living in the community with a family member or caregiver; diagnosed with mild to moderate AD by a geriatrician at least four months prior to referral; capable and willing to express themselves verbally; and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study. The 10-item SPMSQ developed by Pfeiffer (1975) is widely used to evaluate orientation, memory, and concentration. The scores on the observer-rated test range from 0 (normal) to 10 (severe AD), with reported test-retest reliability reported to be 0.8 and a sensitivity of 0.84 and specificity of 0.89 at a cut point of 3 or more errors (Cole, Dendukuri, McCusker, & Han, 2003).

Seventeen individuals with AD were referred to this study, 12 of whom met inclusion criteria and participated in the research. Demographic information is summarized and presented in Table 5.1. The most common diagnosis reported by the caregiver was Alzheimer's disease, followed by depression (7 participants) and hypertension (5 participants). Of the 7 diagnosed with depression, all caregivers reported identification of depression within the past three years, subsequent to the development of noticeable cognitive loss. Five individuals were not accepted in the study; 1 was excluded because he lived outside the state, 1 was unable to communicate, and 3 scored less than 3

Table 5.1
Sample Characteristics

	Persons with AD (*n*=12)
Gender	Male=5 Female=*7*
Age	70-94 Mean 82 years, 2 months
Education	Less than 11 years = 1 High school graduate = 4 College graduate = 5 Graduate education=2
Ethnicity	African American = 1 Hispanic/Latino = 0 White, non-Hispanic = 11
Marital status	Married = 5 Divorced = 1 Widowed = 6
Score on the SPMSQ 3-4 = mild impairment 5-7 = moderate impairment	3 = 4 4 = 2 5 = 2 6 = 3 7 = 1
Living arrangement	Senior housing apartment = 7 Nonsenior apartment = 2 Private home = 2 Family member's home = 1
Co-occurring psychiatric diagnosis	Depression/Anxiety = 7 Mild Cognitive Impairment = 0 Alzheimer's disease = 10

AD = Alzheimer's disease

on the SPMSQ.

Photo-Elicitation

The use of photographs during an interview to encourage dialogue is known as *photo-elicitation*. According to Harper (2002), there are physical differences in the way our brains respond to image and word forms of symbolic representation. Harper (2002) reports the parts of the brain that transmit images are, in evolutionary terms, older than those that transmit verbal information, and that they evoke deeper elements of human consciousness than do words. Harper (2002) believes words and images together use more brain capacity than do words alone, and Harper suggests that this is why photo-elicitation interviews result in not just more but different information. Therefore, photo-elicitation may be an excellent choice for the person with AD.

Photographs used in photo-elicitation can be obtained from either the researcher or the participant; the term *autodriving* is used to indicate that the interview is "driven" by the informant (Hurworth, 2003, p. 2). Cameras are provided to the subjects, and the photographs produced are referred to as *reflexive photographs* because they are from the point of view of—and therefore an expression of—the participant. In photo-elicitation interviews, the subject shares the meaning of the photos, reflecting back from the subject (Harrington & Lindy, 1998). Given the cognitive changes associated with AD, multiple forms of data collection, including photography, may improve the individual's ability to reflect and dialogue, allow participants a chance to speak for themselves, and reduce the researcher's reliance on potentially culturally biased research instruments (Noland, 2006).

Procedure

Prospective participants were contacted by telephone after receiving contact information from the referring provider. During the initial phone call, the study was explained to the individual, who was then asked if he or she would be willing to participate in a study of happiness. Permission was also obtained to contact the family member or caregiver to explain the study and invite him or her to attend the initial meeting and participate in the study. An initial appointment for an in-person meeting was set at that time.

During this call, the caregiver was asked if the care recipient was aware of the diagnosis. Of the 12 participants, 6 were aware of the diagnosis, and the term *dementia* was used throughout the research process. The caregivers of the remaining 6 individuals reported that the participant had been told of his or her diagnosis in the past, but caregivers were uncertain if the participants remembered the diagnosis. For these 6 participants, caregivers requested that the term *memory loss* or *memory impairment* be used during the research process rather than the word *dementia*.

At the first meeting, the study was again explained. Each participant was asked questions to ensure the understanding of the study. Consent was obtained from all participants and a release to reprint photographs was signed by all participants. The SPMSQ was administered to all persons with AD at the initial meeting.

The first 4 participants were given a 12-exposure camera for approximately one week and were asked to take pictures representing situations that inhibit or support happiness. Each person with AD was accompanied by his or her caregiver to assist with logistical concerns. Two additional meeting dates and times were established—the first in seven to ten days to pick up the cameras for film development, and a final meeting was

set approximately four days after film pickup for the interview. For these 4 participants, the final interview occurred approximately 10 to 14 days after camera distribution.

The last 8 participants were contacted and consented in the same fashion as the initial 4 individuals. However, I accompanied the final 8 participants when taking the pictures rather than the caregiver to allow me to understand the original reason for the selection of the photograph and note any change in rationale that might be stated during the interview.

At the first meeting, a date and time was set to take pictures within three days. Pictures were taken by the individual using a disposable camera, my digital camera or the participant's camera phone. The pictures were downloaded onto the researcher's computer and printed out on a digital printer. The final meeting occurred within two to three days after taking the pictures. All 12 participants with AD and the participating caregivers were instructed to take pictures representing happiness from the perspective of the person with AD. The photographs were then used as a springboard for discussion at the final meeting. Study findings related to caregivers are reported in another article (Shell unpublished manuscript, 2013) and are not discussed here.

Semistructured, open-ended questions were used in the interview. The photographs were numbered and placed on a table one at a time, and the individual was invited to talk about each photo and explain in what way the picture represented happiness. Each picture was accompanied by the initial question, *In what way does this picture represent happiness to you?* From that point on, the discussion of the picture was led by the participant's narrative. All participants were able to take photos and answer questions. Field notes were written documenting my observations and including descriptions of the setting, nonverbal behavior of the participants, and my overall

impressions. Personal notes were kept in a reflexive journal. Interviews were audio-taped and professionally transcribed. Transcripts were coded concurrently as subsequent interviews and data collection occurred.

Data Analysis

This research is informed by the theoretical principles of symbolic interactionism, which asserts that the meaning human beings assign to events in their lives is derived from interactions with others (Blumer, 1969). Concepts from the field of positive psychology (Seligman & Csikszentmihalyi, 2000) and Kitwood's theory of personhood (1997) also inform the assumption that wellness within illness is possible in AD and that it is both intrapersonal and interpersonal. That assumption provided the lens through which I interpreted the utility and implications of the findings.

Interviews were digitally recorded and professionally transcribed. Interviews were transcribed, coded, and analyzed as completed, staying close to the data. Transcripts were read and re-read several times to ensure accuracy and to increase familiarity with the data. In vivo codes were initially applied to the transcripts to preserve the participants wording of their ideas and meanings and included in the comparative analysis process. Line-by line coding was then applied which allowed me to identify concepts and processes, and to see the nuances within the data. These codes were subjected to the same comparative and analytic treatment as the in vivo coding. Using NVivo software to analyze the codes, categories were identified which came directly from the data. Focused codes were developed through the comparative process applied to the identified categories which led to the development of themes. Themes were identified and coded for each transcript. Once all individual transcripts had been coded, repeating patterns of

similarities and differences were identified over all the transcripts and were discussed with a colleague who is experienced in qualitative analysis and was familiar with the study and data.. Concepts and categories were coded and compared within and across cases and were clustered using NVivo software. Memos that summarized relevant information for each participant were maintained throughout the research process.

Findings

Five repeating themes emerged across the subject data obtained from the persons with AD: interconnection, nature, transcendence, preservation of self, and joyful moments. Each highlighted core values of the individual. Individual differences were evident within each cross-cutting theme. The findings presented here represent the experience of 12 individuals and are connected to their race, class, gender, and social situation, and therefore may not be generalizable. However, the intention of this study is not to form generalizations but to contribute to our understanding of the experience of happiness in the context of Alzheimer's disease and to identify potential topics for further exploration. Thus, this study is more phenomenological in nature, going in depth in ways that a larger sample would preclude. A summary of the overarching themes, values, and associated photo representation is found in Table 5.2.

Interconnection: I Matter because

Someone Cares for Me

The respondents positioned themselves in a communal context, socially engaged and connected to others whether it was family, friends, or pets. The extent of their

Table 5.2
Values, Subthemes and Corresponding Images Identified

Value	*Subthemes*	*Pictorial representations*
Nature	Self-sufficiency	Garden, gardening tools
	Strength	Person running marathon
	Freedom	Pond
	Peace	Ocean, trees, birds
Interconnection	Nurturance	Family
	Stewardship	Baby shoes, pregnant woman
	Security	Family
	Belonging	Cards
	Companionship	Dog, cat
Transcendence	Gratitude	Family
	Spirituality	Church weekly program
Preservation of self	Acceptance	Family tree
	Perseverance	Sitting in chair
	Balance	Picture of family
Joyful moments	Music	Person singing
	Humor	Couple pretending to get married

involvement with others varied. Their language moved between past, present, and future tenses as they merged their position as caregiver (parent) with their role as care recipient. Family was important to all participants, and all expressed gratitude for relatives, living and dead.

Nurturance

Several women spoke of the importance of mothering in the past tense and of missing that role. For some, the idea of mothering was connected with memories of their young adult years, with thoughts of parenting placed in a personal historical and highly gendered context of heterosexual women of this generation.

LP: Taking care of them when they are little, of course they bring you trouble too. But being a mother, taking care of the children and the house, that's very important. Children need you so much more. But then you miss it when they stop needing you.

TL: I guess I was born for the place, for the position of mom... I'm not a participant the way I was when the kids were growing up.

.

In contrast, fathers spoke about their past role as provider for the family, repeating the gendered, historical context noted in the women, but extended it into the present day.

WM: I would say that the way my son, and to an extent my brother all helped us make this a home instead of a house. I appreciate that. I help (my son) there (son's house) like he helped me here.

MK, the one childless professional female who had worked full time, spoke of feeling "alone" because no other female in the community had a career, acknowledging that few women of her generation followed a professional path absent of children. An urban setting might offer a community of women with occupational experiences more akin to those of MK, providing a sociocultural context that would more likely add to her sense of well-being.

The comments by the women suggest that happiness is understood as a subjective experience that is historically contextualized and influenced by gender—a complex experience beyond the scope of the conventional biomedical model of AD and irreducible to a single affective item on a quality-of-life measure.

MK: We all eat together once or twice a week, but we have nothing at all in common because, you see, she didn't work. I didn't have any children and I worked. I liked it. She brought up three or four children, so she never worked.

Interdependence

Participants were both proud and appreciative of the needed support they received from family members, believing it implied a close relationship between parent and child. While both men and women appreciated the helpful skills of their children, women valued the time and emotional support given by the children.

> DW: If it wasn't for the kids I think I'd be probably upset or bored, but they come often or we talk. Susan and I talk on the phone everyday so it works out.
>
> WM: They (children) helped me. It was a good feeling, it sort of reminded me that we're still together.

Stewardship

Participants mentioned children as an extension of themselves and voiced their hope for a healthy and successful life for future generations. Challenges of life were acknowledged, and wishes for an easy life for grandchildren and great-grandchildren were expressed. Thus, participants acknowledged the contextual nature of happiness and extended this understanding beyond themselves into later generations.

> LP: It's life coming into the world. Hope, new hope, the pleasure of having children.
>
> JC.: It's my way of thinking through—what should I be doing for my family?
>
> TL: Our son... was a handful in many ways and he (is) still moody... my mother's side of the family had depression... I worry about him and his daughter

Belonging

Eleven study participants wished for deep connections to others to provide a sense of belonging; the 12th person expressed contentment for her small social network. A

distinction was made by some between the close friendships that developed in the past and the superficial acquaintances that were reportedly more common in the present.

> TD: I play pinochle and I go in the pool with exercises. I like people there. I don't like everybody, but I do try to be pleasant. I always say hello.
>
> DW: (living at home with husband): I'm saying that once people move into those places (senior housing), they connect (to other residents) and you're the outsider.
>
> LG: We had a Halloween party. I love this film star costume... Last year (I was an) Irish washerwoman- plain green cap, big made out of a mop, a couple gloves, belt, rubber gloves hanging over the belt. (I wish) more people had done it too.
>
> JC: I go to New York, go in and I stand up with a group of men and we sing our hearts out and have a ball.

Companionship

Five participants spoke about the importance of animals as a source of comfort and companionship.

> LG: They're [pets] nice to touch, to listen to, they're nice to look at, they're nice to pet. They're not so nice to clean up their messes but it goes with the territory.

One man, ZS, has been excluded from senior clubs because of dementia-related behaviors that are outside accepted social protocol. For ZS, etiquette is a cognitive construct that has been disrupted by AD, while companionship continues to be an important value irrespective of cognitive impairment.

> ZS: I just enjoy having pets around and now that Lucy died, I don't think I'll ever get another dog. (I) talk (to my other dog) about Lucy all the time and how much we miss and loved her.

Nature: I Am Connected to Other Living Things

Nature—represented through pictures of animals, trees, plants, pond and the ocean—was a central aspect of happiness for 9 participants, though the meaning of nature was individualized, reflecting self-sufficiency, strength, peace, and freedom.

Self-Sufficiency

For some, the tending of a garden served as more than a source of productive work. It also represented the ability to continue to function independently as they did when they experienced wellness uncomplicated by AD. The garden became a manifestation of the part of themselves that they perceived of as *healthy,* and they were proud of both the final product and their continued ability to make a contribution to others.

> DW: I've always liked to work outside. I don't consider it work; I consider it a joy.
>
> LP: It's the relaxation that comes from doing work that's not taxing - it's not that fussy work, it's not taxing work.

Strength

For others, nature was the place of past athletic challenges and achievement, a reflection of healthier days. This was a theme that was expressed in the past tense by individuals who were currently using devices to assist in ambulation as a way to share their well self.

> LG: I did a lot of hiking when I was younger on the trail. [We'd think], *We will make it to the top, we will—yeah we made it!*
>
> ZS: (Running in the NYC marathon) was the most fantastic part of my life. I've

had a lot of good experiences in my life but that was the best...Never felt better then when I was running and it's disappointing that I can't, of course I can't, having a cane and a lifeline and a medic alert bracelet, it slows you down.

TL: (When I'm outdoors) I'm free, almost get to smell the air. And most of the time, most of the time I actually see something that I think is attractive. Oh look. Here comes the moon. It won't be too long before it's full again. We get some beautiful moons, even outdoors that way. I always liked to look at the moon.

Peace

Nature provided a source of peace and spiritual connection for several participants who used language in the present tense. In this way, nature served as a route to transcend the disease, separating the self from the disease.

LG: (Nature makes you happy but) not the kind of grinning happy—you know, just the soul; it feeds you so.

EP: Yeah, trees a bunch of trees... make (me) think of peacefulness. You don't see many in the city.

Freedom

Nature also represented freedom—freedom from unwanted responsibility or expectations of others, freedom from an unhappy living situation, or freedom from reminders of aging and diminished capacity. The discourse in the present tense referred to freedom from the present life, which is experienced as challenging.

MK: It looks like you're not here (in senior housing), but on the other side.

TL: I'm afraid to participate. I don't want the responsibility (of friendship) and I'll always have to depend on somebody.

Transcendence: I Am Part of Something Greater

Transcendence expressed as gratitude and spirituality conveys a sense of appreciation and awe of a world that is larger than one's self. Eleven of the participants spoke of gratitude. The most frequently mentioned source of gratitude revolved around family.

Source of Gratitude: Love of Family

Several spoke of gratitude for the love and support of family and appreciation of the assistance given by a spouse.

> JC: I have a family that I love. I have the love of my family, and, boy, I'm the luckiest son of a bitch in the world.
>
> AA: [My wife] is doing things for me over and beyond. I take something like, I don't know, close to 20 pills a day.

Source of Gratitude: Health of Self and Family

The participants demonstrated an understanding of wellness that extended beyond the biological model, including physical, emotional, and social health and the presence of harmonious interpersonal relationships. Participants viewed family as an extension of themselves and were grateful for healthy family members.

> TL: [I see my sons] cooperating when they hadn't in a while and I think, whew, thank you, Lord, because it really . . . I guess maybe I thought [family dissention could] be inherited too.
>
> LP: Happiness to me is seeing my family happy (and) healthy.

One participant considers his physical changes to be part of the aging process. He voiced appreciation of his current level of health, understanding that future decline may occur.

WM: You don't think about getting old. It's way down the hole. One day it hits you, and I am very thankful that things have worked out for me.

Source of Gratitude: Independence

The need for housing to address physical needs and support optimal independence was acknowledged by all participants on a conceptual level. However, the response to accommodations of physical disability was based on personal needs. Speaking in the present tense, one individual currently using a cane and who anticipated deterioration in his physical condition expressed gratitude for safe housing.

ZS: [I] like Seaside [senior housing].You can walk for miles without getting wet.

Another individual who lives in the same setting but who does not have physical challenges found the presence of walkers and wheelchairs a depressing prognosticator of challenges to come.

MK: It's depressing seeing all those wheelchairs and walkers.

Spirituality

Spirituality was mentioned by 11 participants during the interview, either directly or as an aspect of other themes. This group expressed spirituality outside of the boundaries of religion, not as defined by rules such as attendance at services, and expressed it in very personal terms.

No one identified disease as impacting his or her decision to participate in religious observances or as a challenge to his or her previous belief system. The present tense was used to discuss spirituality, reflecting continuity from previously held beliefs.

> AA: It isn't that I don't believe in God. I just don't think... That's not a question. It's not just a question of believing but it's thinking too, and I put them together and I wouldn't be surprised. I wouldn't fall over. I'd be very happy if I get in some door and go in, but I'm not counting on it.
>
> WM: Sometimes I feel like I'm not doing the right thing by [not] going to church all the time. By the same token, I'm not a sinner as such; I pray every night. I'm comfortable with that. I don't have to make an appearance at the church.

Reverence

God/ spirituality/higher power was identified by 2 persons as helpful in their acceptance of AD. This appeared to be part of a broader belief system, not limited to a specific situation or experience but rather encompassing all aspects of life.

> JC: The good Lord gave me [AD] . . . . Lord said, "Accept the job, John," and I have.
>
> TD: So I got an angel ... or whatever it is, God, whatever.

Preservation of Self: Life Is Still Good

Making meaning of AD took many forms, with various strategies used to adapt to diminished ability while preserving the self. None of the participants had received professional counseling; coping strategies were independently developed and implemented and were congruent with the generational value of self-reliance, which shunned counseling as an indication of weakness. The derived meaning of the AD

experience was therefore limited by the historical and sociocultural context that informs one's thoughts and understanding.

Acceptance

For some, accepting cognitive decline by normalizing impairment as part of aging allowed for preservation of self as a healthy senior rather than the pejorative social understanding of a demented person. Others chose to take control of their life and their thoughts, finding ways to accept decline while maintaining a positive attitude.

> WM: I realize that I'm not the person physically or mentally that I was 10 or more years ago.
>
> MK: I know the limitations of old age. I don't sit around fretting about it, but I know it.
>
> ZS: There's always something that can make you happy. Life is what you make it.

Some were less certain of the future, cautiously accepting the present condition while also expressing fear of the unknown.

> TD: Last night, this one woman kept saying, "I don't remember this." I said, "That's why we're here," but it is hard for me. I don't speak sometimes and I do forget things.
>
> DL: (We're alright now, but) I think (husband) has more problems with memory, oh yeah, without question. And it happened so much faster. Not sure what we'll do (if it gets) worse.

Perseverance

All participants are finding ways to adapt to dementia-related changes. All are making detailed lists of appointments and activities. One participant is fighting the

cognitive and language difficulties that have accompanied the disease by keeping lists of forgotten words and names of composers so he can test himself during the day.

> AA: I'm dealing [with] a problem . . . my mouth goes faster than my brain. You noticed I get up to a point—there's a door there. I have to wait . . . I'm trying to train myself to talk a little slower.
>
> JC: (It) takes time to get that you have a problem with your head - memory or whatever it is... I've been known to turn around and say, "I can't remember what I should be telling you and what I should be holding back from you but I'm going to give you how I feel."
>
> TD: And I looked at some of them and I don't remember who they were.
>
> (I) never would remember it ... he had to write it down for me.

Balance

A view of life as a balance of positive and negative experiences provided a context for acceptance of the deleterious effects of Alzheimer's disease as payback for a life filled with multiple blessings.

> AA: I know I got luck in my birthing but someday I'm going to pay up for that. I don't have to go very far to look and see where I'm not what I was 40 or 50 years ago or 30 or 20 years ago.
>
> JC: God gives both good and bad things. If you accept one, you must accept the other.

The role of a deity in the development of Alzheimer's disease was mentioned by 2 individuals. A limitation to this study is that the participants all live in the northeast portion of the United States, an area with religious beliefs based on the Judeo-Christian

tradition. Results may not be generalizable, and a sample from other parts of the United States might produce different attitudes and beliefs.

JC: It's something that the good Lord gave me. It's something that the good Lord said, "Accept the job it, John," and I have.

AA: I had a hell of a good time in a sense for 75 to 77 (years, that is) when it started creeping in. I got all that good and you put it on me, the weight. I'm really heavy with the good stuff and I guess—*is God doing this to me?*

Joyful Moments: Still Happy After All These Years

For 11 participants, happiness continues in the presence of Alzheimer's disease, though the experience changed and required effort for some.

DW: Happiness changes to contentedness over time. . . . Happiness comes from within.

LG: I don't have that many ha ha happy times. . . . (Happiness) is soul satisfaction.

EP: Well, that sounds like a happy time—no problems.

One participant denied feeling happy. She feels isolated living in senior housing, has no surviving family, and has not met anyone in the community she considers to be a friend.

MK: I'm not happy, but I'm not unhappy. I don't have fun anymore. That's the way it is.

Wisdom gained over the lifetime allowed several to identify specific interventions that improve mood in the present by reflecting on effective strategies in the past.

. LG: Yeah, sometimes I'm lonely. . . Sometimes I can correct it by doing or going

with people to the auditorium, but most of the time I'm happy.

TD: I have times when I'm not doing good. Sometimes I just say, "Get out!" The other day, I just go all the way around, all the way around [walking].

Music

Music was identified as a source of happiness for many, crossing temporal boundaries by bringing together memories of family alongside current experiences of sharing music with others. Singing, playing instruments, and listening to music was mentioned both as a pleasant social activity and an enjoyable musical event. It also provided an escape to an earlier time for those for whom music has been a lifelong value.

Music connected individuals to previous generations and offered a historical context to life events. Some remembered war songs popular during World War II.

MK: My mother always sang and we always did a lot of singing. When we had company over, we always had a piano and my mother played by ear.

LG: My early memories (as) a child were Mommy sing to me.

LP: (Music) reminds me of my mother because my mother would go around the house all the time singing—ooh ooh ooh ohh (laughter) . . . she had a very pleasant voice . . . (I) knew all the old songs because of her before my other friends knew them.

Music also served as a connection to the present. Singing groups provided a social activity and an end to silence. Two individuals are members of singing groups that rehearse weekly and have occasional performances.

MK: We have rehearsals. . . . We all just walk over there. We have an hour or so to rehearse.

LP: I don't like silence. When I'm at home I've always got some kind of radio on.

Humor

Alzheimer's disease and laughter are not mutually exclusive. For some, fun and laughter continue to be sought-after experiences.

LP (referring to a picture): It's the comedy, that's the key. . . . It's a funny picture.

LG: Every once in a while I laugh uproariously, mostly because of the cat.

Activity Leads to Happiness: Yes and No

This final emergent theme was not crosscutting, but remains significant in that it illustrates the intricacy and contextual nature of happiness. Two persons reported opposite extremes of activity level with one common outcome: happiness. One participant identified being active as desirable, but for the other being active is distressing. Looking at the social historical context of each individual brings clarity to these opposing sentiments. This example suggests the complexity of a construct of happiness that is formed during childhood, one that is historically and socially contextualized and remains intact in early stages of AD. This theme was represented in only two accounts. However, it highlights the importance of having ways of assessing happiness or well-being that can account for individual differences and interpretations.

Active Equals Health and Happiness

LP was diagnosed with rheumatic fever as a child. A residual heart murmur was identified, and treatment included activity limitations and inability to participate in sports or gym class. LP now equates activity with health and inactivity with illness.

LP: It's very hard as a child just to sit around doing nothing. I wasn't allowed to

play any sports. . . . Now, I don't know how to sit still.

Quiet Equals Peace and Happiness

EP grew up in a poor family. She reported loud, violent arguments between her parents and frequent moves to evade bill collectors. She married a man who shared her desire for a quiet life, and they raised their family in this fashion. She prefers to stay in the apartment she shares with her daughter rather than attend a senior center. EP equates quiet with peace and contentedness.

EP: Not a lot of things happen when you get older; quiet, just the way I like it.

Discussion

In this section, the use of photo-elicitation in persons with AD is reviewed. This is followed by a general observation of the participants. The findings of the study are then presented, beginning with the presence of happiness in the lives of the participants and followed by the overarching theme of values: interconnection, nature, transcendence, preservation of self, and joyful moments, as well as individual differences and interpretations within each. The discussion concludes with suggestions for future studies and identification of study limitations.

Use of Photo-Elicitation with Persons with Alzheimer's Disease

In this study, the subjective experience of happiness in persons with mild to moderate Alzheimer's disease was explored through the use of photo-elicitation. The initial 4 participants with AD were accompanied by their caregiver during picture-taking; the final 8 were accompanied by me. This was done to determine if there was an inability

of the participants to remember their rationale for taking some of the pictures. I believe this change may have allowed some participants to more easily remember their reason for photo selection. However, the photographs were not used as representation of objective truth but rather as a springboard for dialogue. Through discourse, the experience of happiness was cocreated by me and participant, as occurs when pictures supplied by the researcher are used during the interview. I consider the findings drawn from the first four interviews to be as valid as the findings drawn from the final eight. This belief was supported in follow-up interviews with 2 of the initial 4 participants in which my categories and interpretations were confirmed as reflections of their ideas.

I met with each participant twice before the photo-elicitation interview took place—once to explain the study and once to either pick up the camera for film development or to accompany the participant while taking photos. It was clear that by the third meeting, the participants felt comfortable sharing their personal stories with me. Time spent establishing a relationship prior to the interview seems particularly important in this population where self-esteem and self-confidence is challenged by dementia-related deficits and may hinder comfort in conversation.

The use of photographs in this study served two important purposes. First, it provided a concrete representation of the abstract concept of happiness, allowing me to see what could not be communicated with words but could be extrapolated and then reconstructed through discourse. Second, the photographs and the ensuing dialogue provided the participant an opportunity to reflect on the experience—and therefore reflect on their life. In this way, meaning was conveyed and insight developed for both me and the participant.

For example, LP spoke about being teased and ostracized by other children because she was unable to participate in physical activity. As she discussed her need to "be busy," she realized the need to be active was in part a response to that piece of her life story. This is just one of several instances where a new insight was revealed to the participant. In each case, this unintended outcome was welcomed by the individual.

AA: I never thought of it that way. I appreciate that. Makes me feel a little bit better.

General Observations of the Participants

Participants in this study varied in cognitive and language abilities, but all were able to communicate their thoughts with some limitation, mostly related to word retrieval skills. All participants had some initial difficulty remembering that they had taken a photo, but they remembered after a few moments of thought. Some initially offered alternate explanations than originally stated. Ranging from mild to moderate AD, the participants were all able to reflect on happiness in the present, past, and future tenses and to engage in a discussion of what happiness means to them in a fashion as sophisticated and nuanced as persons who are not experiencing cognitive decline.

While this sample is small and does not represent a diverse population, it does indicate a capacity for conversations about personal preferences, values, goals, and quality of life issues. Each individual should therefore be assessed before assuming lack of capacity for meaningful dialogue and, where possible, these conversations should be actively pursued before disease progression occurs.

Presence of Happiness in the Lives of Persons with Mild to Moderate Alzheimer's Disease

Perhaps the first and most obvious finding is that persons with mild to moderate Alzheimer's disease can experience happiness, though the experience of happiness may change over time and disease progression. For example, music was identified as a source of happiness, taking on different meanings and able to transcend temporal boundaries irrespective of cognitive ability and presence of disease. This simple observation of subjective happiness in persons with Alzheimer's disease suggests an individual can live a meaningful life despite the presence of a life-limiting mental illness such as Alzheimer's disease. It also changes the common understanding of Alzheimer's disease from a "fate worse than death" to one that includes the possibility of happiness, contentment, and hope. Further, it suggests that happiness does not depend solely on full cognitive function, as it continues even in this sample of persons with cognitive impairment.

Admittedly, the ability to reflect on and process these images and stories is itself a cognitive process. However, in this study, the subjective experience of happiness is explored through an intersubjective process by creating a common space of engagement where the person with AD can articulate his or her thoughts and subjectivity. In this space, subjective happiness can be communicated in a way determined by the participant and constructed through meaningful dialogue and interaction.

The meaning of human subjectivity and intersubjectivity is a topic of interest in both the philosophical and psychoanalytical literature, a review of which is beyond the scope of this article. However, one aspect of debate among philosophers is the question of whether subjectivity is the result of, or is proceeded by, interaction with others (Frie &

Reis, 2001). An analogous question is whether happiness is a thing that resides inside the person waiting to be accessed, or is constructed in and through meaningful interaction with others. This question is outside the purview of this research. However, my belief is that happiness can be experienced and communicated even as cognition declines and that emotional fulfillment should be a treatment goal for persons with Alzheimer's disease.

The Overarching Theme: Values

The overarching theme found in the data is the importance of values. Based on work in the fields of positive psychology (Park, Peterson & Seligman, 2004) and social psychology (Schwartz, 1994), I defined a value as a desirable goal that serves as a guiding principle in one's life; transcends specific situations; and guides one's assessment of behavior, events, others and ourselves.

Through analysis of the transcripts, the connection between the continued expression of and engagement with personal values and a sense of well-being became apparent. Five cross-cutting values were identified by a majority of participants: nature, interconnection, transcendence, joyful moments, and preservation of self. Although these five themes were shared by the majority of participants, they were quite individual in their construction, reflecting the complexity within each. Nature represented *strength* to earlier athletes, *self-sufficiency* to gardeners, *freedom* from responsibility to those struggling with cognitive impairment, and *peace* for many who described this as a lifelong value. One person remembered the exhilaration of reaching the summit during a hike. No longer able to walk independently, nature has become a spiritual experience for this person, suggesting that values remain intact but may be experienced differently, though in concert with changing ability.

Participants expressed a desire to connect with others on a personal level, though individual differences were noted. Interconnection and social engagement was noted to provide *security, belonging,* and opportunities for *nurturance, companionship,* and *stewardship*. The desire for *companionship* was shared by most participants, though to differing extents. Some participants preferred limited interaction for a variety of reasons, including feeling incapable of the perceived "responsibility" associated with friendship and the fear of embarrassment from dementia-related impairment. Others felt unable to forge new friendships due to geographical isolation or the inability to find another with shared interests or life experiences. The participant who expressed the greatest sense of unwanted isolation also denied feeling happy, suggesting the ability to live in concert with one's values is important to the presence of well-being.

Transcendence in the form of gratitude and spirituality was expressed directly and indirectly in the interviews. *Gratitude* was an important aspect of happiness, thus supporting previous studies that suggest gratitude leads to an increase in positive affect and a decrease in negative affect (Emmons & Mishra, 2011). For some, faith had a significant role in the acceptance of the diagnosis of Alzheimer's disease. A small number of people identified religious faith as an important component of happiness. This may reflect values of the northeast section of the United States, or may just reflect the values of these 12 individuals. However, looking at religion and spirituality more broadly to include all expressions of transcendence suggests that spirituality has a larger place in happiness and well-being.

Preservation of Self

Recognition and making meaning of loss—predominantly impairment of memory and mobility—was expressed in all of the interviews and challenged the individual's understanding of himself or herself. Acceptance was sought through multiple strategies, including normalizing dementia-related changes as part of aging, seeing life as a balance of good and bad events, suggesting impairments are "payback" for having led a good life, and modifying activities to minimize challenging situations. These approaches provided ways for the individual to find benefit in ordinary life events, stay involved in meaningful activities, and maintain a positive attitude despite experiencing loss and an uncertain future.

Folkman's suggestion that persons facing chronic stressful conditions can participate in meaning-based coping is supported in this study of persons with Alzheimer's disease. Folkman (1997) identified three meaning-based processes used to cope with a stressor: using positive reappraisal, whereby the individual reinterprets the situation in terms of personal values; revising goals; and finding meaning through spiritual beliefs. All three were reported by research participants as mechanisms used to preserve self and cope with dementia-related changes. This suggests that interventions aimed at developing meaning-based coping strategies that honor the personal values of the persons with Alzheimer's disease —such as reappraisal of goals, situations, and loss through the lens of individual values and beliefs—may reduce the negative impact of Alzheimer's disease, increase resilience, and enhance the presence of happiness and well-being for individuals with mild to moderate Alzheimer's disease.

Study Limitations

The sample size is small, limited to one state in the northeast United States, and may not be generalizable to other areas. Findings may be connected to class, race, and social situation, and may not be generalizable. Lastly, the sample was recruited from referrals by outpatient geriatricians and may not reflect all persons with mild to moderate Alzheimer's disease.

Future Studies

This research, like most qualitative research of the lived experience of Alzheimer's disease, was conducted with a small sample of individuals with mild to moderate disease. As a result, there is a limited understanding of the experience of those in the more advanced stages of illness. Longitudinal studies examining changes in the subjective experience of happiness and personhood over time are needed to provide this information.

Assessment tools for clinicians that lead to a contextual and historical understanding of the individual's values and beliefs are needed. Consideration of the heavy demands currently placed on healthcare workers must be taken into account to allow these tools to be used in various levels of care. Interventions are needed that support the values identified by the individual, rather than focusing solely on activity level and interests. Additionally, replication in various communities throughout the United States and internationally are needed to confirm the role of values in Alzheimer's disease.

Finally, outcome measures have traditionally reflected the perspective of the caregiver or researcher. Outcome measures of happiness and quality of life are needed

that reflect the perspective of one with Alzheimer's disease to ensure that the values of importance to the participant are supported.

Conclusion

Analysis of the transcripts highlights the importance of both the subjective and the historical perspective of the individual in understanding the experience of happiness. The importance of nurturance as reported by mothers and the provision of support to family members as reported by fathers highlight the historical and gendered contextual nature of happiness in this population. The uniqueness of the individual accounts within each value identified—interconnection to others, nature, preservation of self, and transcendence—support the idea that values are not just something we have within ourselves grounded solely on cognition, but are historically and contextually based, constructed in relation to other people. Values, then, are not universal, but can only be understood for each person by spending time with him or her to draw out expression of those values. The only way to obtain a contextualized understanding of happiness and other values, such as personhood in AD, is to spend time with the person and through constructive discourse and interaction, deconstruct the experience to better understand the contexts upon which it is based.

It is clear the overarching theme of the interviews was personal values. The participants talked about doing things, but that was not really the point. The point was to express a deeply held value emanating from a profound historical place central to the individual and minimally impacted by cognition. Models of personhood in AD that emphasize cognitive ability may be missing the point.

This research suggests that placing emphasis on the identification of core values can best support personhood. If cognition is omitted as a prerequisite to personhood and core values are understood to remain in illness, the separation between “them” and “us” is lessened and a shared universal understanding of what it is to be human can develop. Interventions that identify and support one’s core values, adjusted to the capability of the individual, may be used to maintain personhood regardless of cognitive ability or presence of AD. In this existential humanistic approach, there is potential to support a meaningful life, including the presence of happiness, by going beyond observable behaviors to understand the underlying values of the individual, with or without the presence of Alzheimer’s disease.

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CHAPTER 6

HAPPINESS IN PERSONS WITH ALZHEIMER'S DISEASE: THE PERSPECTIVE OF THE CAREGIVER

Abstract

Happiness and quality of life are cited as important goals of Alzheimer's disease care. However, because those with dementia often have cognitive and communication limitations, reports obtained from staff and family caregivers have been used to measure quality of life for people with Alzheimer's disease. However, proxy reports have been shown to differ from appraisals obtained by the person with Alzheimer's disease. Various reasons for this discrepancy have been suggested, but exactly why this occurs is unclear.

This article reports on a qualitative study comparing reports about sources and perceptions of happiness in a sample of 10 persons with mild to moderate Alzheimer's disease with the reports of their caregivers. Both members of the caregiver-care recipient dyad reported sources of happiness from the perspective of the person with Alzheimer's disease, using photo-elicitation and individual interviews for data collection. Results of this study demonstrate that lifelong values, historically and contextually based and constructed in relationship with other people, continue to be important to the person with Alzheimer's disease. Study results also point to the caregiver's lack of awareness of these values, possibly reflecting a constricted view of the person with Alzheimer's disease that excludes the possibility of insight or reflexive thought, thus a limitation of personhood.

Introduction

The term *dementia* is used to refer to a large group of disorders including Alzheimer's disease (AD) caused primarily by neurodegenerative changes in the brain and marked by progressive decline in social, cognitive, and physical function. The majority of the information currently available about AD is structured by research based on a biomedical model focused on pathology and dysfunction with evaluative research measured on biomedical outcomes. Little attention has been paid to the subjective experiences of the individual (Hubbard, Down, & Tester, 2003; Lyman, 1989). This strictly biomedical view has been challenged by Kitwood (1997), Sabat (2006), and others who suggest social environment and personal history may affect the expression and progression of AD symptoms. As a result, there has been an increased interest in the subjective (emic) experience of AD and its influence on quality of life.

There are inherent challenges to studying the subjective experience of persons with AD, including impairments in language, memory, and cognition, which may limit verbal communication and thus the ability to provide information (Hubbard et al., 2003; Moyle, Murfield, Griffiths, & Venturato, 2012). To address these concerns, observational tools and proxy reports have been used in quality-of-life studies in place of self-report by the participant. However, research suggests a weak to moderate association between caregiver and patient ratings at best, with proxies tending to report more functional impairment, more depressive symptoms, and lower levels of psychological well-being than the person with AD (Coen, 2013; Logsdon, Gibbons, McCurry, & Teri, 2002; Neumann, Araki, & Gutterman, 2000; Novella et al., 2001). Understanding the processes that may lead to the discrepancy between caregiver and care recipient reports may guide

health professionals to a more accurate interpretation of both proxy and patient reports and a more nuanced understanding of the experience of AD from the perspective of both the person with AD and the caregiver.

There is another reason to study the subjective experience of AD from the perspective of both the diagnosed individual and the caregiver. Kitwood's (1997) concept of personhood suggests that personhood is socially constructed, the result of the interaction and communication between the person with AD and the social environment of which the caregiver is a part. This would also be true for people who experience cognitive differences, because their situations and experiences take place within a human, interpersonal context that includes participation in a culture that transmits and interprets meaning. Exploration of the experience of AD through the eyes of both members of the dyad, therefore, may offer insight into the intersubjective space occupied by both the caregiver and the care recipient, including ways to support personhood for both.

In this article I review the biomedical model of AD and Kitwood's theory of personhood followed by a comparison of quality-of-life reports by the caregiver as proxy and by the person with AD. I then report on a qualitative study to explore the experience of happiness in persons with AD from the perspective of the individual with AD and their caregiver, noting the sources of happiness identified by the caregiver and the extent to which they are consistent with, or divergent from, sources identified by the care recipient.

Context of Current Research

Dementia is an overarching term used to describe a large and complex set of progressive disorders marked by progressive neurologic decline; of those disorders, Alzheimer's disease (AD) is the most common. This worldwide number is expected to

grow from 35.5 million in 2010 to 65.7 million by 2030 (Alzheimer's Disease International, 2012). In mild AD, a person may experience memory loss yet still remain able to communicate, attend to personal care and activities of daily living, and participate in socially meaningful ways.

The dominant disease model in the United States is the biomedical model that assumes disease is solely located in biochemical processes; it excludes social, psychological, and behavioral dimensions of the illness (Engel, 1977). The biomedical model has been increasingly challenged by Kitwood (1997), Sabat (2003), and others who suggest psychosocial factors play an important role in disease expression and progression. To date, research has predominantly focused on neurobiological factors of the disease and the influence of the disease on the caregiver, with little attention given to its effect on the person with AD or the interaction of the person in his or her social context and environment (Cottrell & Schultz, 1993).

Personhood

Contrary to the biomedical model that associates cognitive loss with "loss of self," Kitwood (1997) believed each event experienced by a person with AD has both a psychological and biological component, and that the interplay between these two factors and the social environment influences personhood. In this broader model, psychosocial factors—including the reaction of others—affects the quality of life, expression of cognitive abilities, and ability to live a meaningful life for the person with AD (Kitwood, 1997; Sabat, 2004). Thus, personhood is not dependent on cognitive ability but rather constructed through interaction within the social environment, with the caregiver taking on the important role of the social "other" (Kitwood, 1997). Advocating person-centered

approaches in AD care, Kitwood (1997) emphasized communication, relationship with others, and the viewpoint that the person with AD has personhood and rights, including the right for his or her experiences to be explored through research (McKeown, Clarke, Ingleton, & Repper, 2010).

Application of Kitwood's (1997) theory of personhood underscores the important contextual nature of the individual's relationship with the caregiver as cocreator in the AD experience. Research of the caregiving aspects of the relationship have been limited to a constricted, one-directional view of assistance provided by the caregiver and accepted by the care recipient (O'Connor et al., 2007). This study—which looks at the subjective experience of happiness in persons with AD and ways in which it is understood, recognized, and supported or hindered by the caregiver—begins to shed light on the bidirectional, interpersonal, interaction upon which Kitwood's view of personhood is based.

Subjective Assessment of Quality of Life by Proxy and Person with Alzheimer's Disease

In Alzheimer's disease, as in other diseases without a cure, the improvement of quality of life by maintaining optimal physical and emotional health is an important treatment goal as part of the effort to reduce disability and suffering. Current AD quality-of-life measures are based the work of M. Powell Lawton (1994, 1997), which stresses a multidimensional evaluation of AD that includes both subjective and objective appraisal. Most quality-of-life tools include a component of positive affect and psychological well-being. However, measuring this concept in the context of AD is challenging because of variability in the method of response (self-report vs. proxy); terms such as *well-being*,

positive affect, and *happiness* that are used interchangeably and without clear definitions; and variability in the choice of foundational constructs.

Proxy reports have been used to evaluate quality of life to compensate for cognitive and language limitations occurring with AD, a practice that fits the biomedical disease model of AD but contrasts with Kitwood's holistic view of the person, which suggests that the individual can continue to meaningfully assess quality of life. Past evaluations by people with AD and proxy responders point to disparity between the two, with AD respondents frequently rating their quality of life and psychological well-being higher than rated by the proxy, suggesting that caregivers may be influenced more by dementia-related loss than by a positive sense of remaining capacity (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Edelman, Fulton, Kuhn, & Chang, 2005; Lum, Lin, & Kane, 2005; Neuman et al., 2000). Caregiver factors that may influence proxy reports of quality of life include the caregiver's assessment of the cognitive impairment, depression, agitation, and impairment in activities of daily living in the person with AD; caregiver burden; the prior relationship between the partners; the proxy's own expectations and belief system; and the stigma of AD (Moyle et al., 2012; Scocco, Fantoni, & Caon, 2006; Sloane et al., 2005). Finally, it may also be that the construct used by individuals to assess quality of life changes over time or as the disease progresses.

This study looks at the experience of happiness through the eyes of both the caregiver and the person with AD, offering insight into the complexity of their daily interactions and how those interactions contribute to or distract from the happiness and sense of personhood for both individuals. Expanding our understanding of happiness and

quality of life from the more conventional study focused on either the view of the proxy *or* the person diagnosed with AD to research attentive to the intersubjective space occupied by *both* persons may lead to interventions to improve quality of life for those with mild to moderate Alzheimer's disease and their caregivers.

Study Purpose

After years of looking at persons with AD through the lens of the biomedical disease model, Kitwood (1997), Sabat (2004), and others have opened the doors to a fuller understanding of the disease, including the larger psychosocial environment and situation of the person as a member of society worthy of a meaningful life. Interest in quality of life and optimization of physical and emotional health in AD has led to the development of assessment tools that tended to reduce happiness and well-being into a single measure of affect or mood, thus minimizing the usefulness of results. Until recently, attention has been paid to the caregiver's report of quality of life of the person with AD while ignoring the perspective of the person with AD (Cotrell & Schulz, 1993). We are only recently beginning to understand that persons with AD can evaluate and communicate subjective quality of life. This, plus the inconsistent quality-of-life appraisals by care recipients as compared to those of their caregivers, suggests a need for a greater understanding of both the experience of happiness for those with AD and the discrepancies of their reports.

The research reported here is part of a larger study to explore the subjective experience of happiness in persons with mild to moderate AD and to provide a more nuanced understanding of the discrepancy between these findings with that of caregiver perception of his or her care recipient partner. This article reports on the presence of

happiness and well-being in AD from the perspective of the caregiver, comparing and analyzing the perspective of the person with AD to that of the caregiver.

In the next section, I begin by reviewing the methodology, including photo-elicitation, used in this study of persons with AD. This is followed by a general observation of the participants. Next I present the findings of the study, beginning with themes of interconnection, nature, activities for activity's sake, and response to the diagnosis of AD, followed by the overarching theme of values. I conclude with suggestions for future studies and identification of study limitations.

Methodology

Design

This was a qualitative interpretive study involving semistructured interviews and the photo-elicitation method of data collection. Transcripts of interviews were analyzed using interpretive design to develop shared themes of the key elements of the participants' experience of happiness. All activities conducted during this study were reviewed and approved by the Institutional Review Board of the University of Utah. The names and initials of all participants have been changed to protect confidentiality. Consent and a release to reprint photographs was signed by all participants.

Photo-Elicitation

The use of photographs during an interview to encourage dialogue is known as *photo-elicitation* (Harper, 2002). Photographs were taken by the participant—a method termed *autodriving* to indicate that the interview is "driven" by the informants (Hurworth, 2003, p. 2). The photographs produced by participants are referred to as

reflexive photographs, meaning they are from the point of view of the subject and thus an expression of the participant. The photographs become the starting point of the interviews, with each subject sharing the meaning of the photos, reflecting back from the subject (Harrington & Lindy, 1999).

AD is associated with cognitive limitations that may hinder verbal communication. Therefore, multiple forms of data collection, such as photography, may improve the individual's ability to reflect and converse by providing participants a chance to speak for themselves through a visual media (Noland, 2006).

Participants

Participants were referred to the study by geriatricians in two northeastern United States communities. A letter describing the study, the inclusion criteria, and requesting referrals was sent to geriatricians listed in public records and professional organizations in these two communities. Inclusion criteria for this study were English-speaking adults age 70 or older; living in the community with a family member or assisted by an identified caregiver; diagnosed with mild to moderate Alzheimer's disease by a geriatrician at least four months prior to referral; ability and willingness to express themselves verbally; and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study. The ten-item SPMSQ developed by Pfeiffer (1975) is widely used to evaluate orientation, memory, and concentration. The scores on the observer-rated test range from 0 (normal) to 10 (severe AD), with test-retest reliability reported to be 0.8 and a sensitivity of 0.84 and specificity of 0.89 at a cut point of 3 or more errors (Cole, Twelve of the 17 individuals with Alzheimer's disease referred to this study met

inclusion criteria and participated in the research. Five were male and 7 were female, with a mean age of 87 years six months (range 70 to 94). Eleven participants were White; 9 of those originated from the United States, 1 from the United Kingdom, and 1 from Portugal. One participant was Black and originated from the United States. Five participants were married and living with their spouse. Seven lived in senior housing apartments, 2 lived in houses they owned, 1 lived in a home owned by children, and 2 participants lived in a nonsenior apartment. In terms of education, 2 participants had master's degrees, 4 had bachelor's degrees, 2 had attended secretarial school, 3 had completed high school, and 1 had completed the 10^{th} grade. The most common diagnosis was Alzheimer's disease followed by depression (7 participants) and hypertension (5 participants). Of the 7 diagnosed with depression, all caregivers reported identification of depression within the past three years, after the development of obvious cognitive loss. Five individuals were not accepted into the study; 1 was excluded because he lived outside the state, 1 was unable to communicate, and 3 scored less than 3 on the SPMSQ.

All caregivers were invited to participate in the study. Of the 10 caregivers who agreed to participate, 5 were spouses, 2 were daughters, 2 were sons, and 1 was an unrelated caregiver. The inclusion criteria for the caregivers were that they be English-speaking and willing to express themselves verbally. Two caregivers declined to participate in the study due to a limited length of time caring for the participant. Sample characteristics of all participants are found in Table 6.1.

Procedure

After I received contact information from the provider, each participant was contacted by telephone. During the initial phone call, the study was explained to the

Table 6.1

Sample Characteristics

	Persons with AD (*n*=12)	CGs (*n*=10)
Gender	Male=5 Female=*7*	Male=3 Female=*7*
Age	70-94 Mean 82 years, 2 months	Child/Non-relative CG=54 Spouse CG= 86
Education	Less than 11 years=1 High school graduate=4 College graduate=5 Graduate education=2	Not asked
Ethnicity	African-American=1 Hispanic/Latino=0 White, non-Hispanic=11	African-American=0 Hispanic/ Latino=1 White, non-Hispanic=9
Marital status	Married=5 Divorced=1 Widowed=6	Married=8 Divorced=1 Widowed=1
Score on the SPMSQ 3=mild impairment 7=moderate impairment	3=4 4=2 5=2 6=3 7=1	Not administered
Relation to person with AD	Not applicable	Spouse=5 Son=2 Daughter=2 Non-relative=1
Living arrangement	Senior housing apartment=7 Non-senior apartment=2 Private home=2 Family member's home=1	With person with AD
Co-occurring psychiatric diagnosis	Depression/anxiety=7 MCI=0 Alzheimer's disease=10	Depression/anxiety=5 MCI=1 Alzheimer's disease=1

AD= Alzheimer's disease; CG=caregiver; MCI=Mild cognitive impairment

individual, who was then asked if he or she would be willing to participate in a study of happiness. An appointment was set for an initial in-person meeting at that time. Permission was also obtained from the participant to contact the family member or caregiver to explain the study and invite him or her to attend the initial meeting and participate in the study. During this call, the caregiver was asked if the care recipient was aware of the diagnosis.

Of the 12 participants with AD, 6 were aware of the diagnosis, and the term *dementia* was used throughout the research process. The caregivers of the remaining 6 individuals reported that the participant had been told of his or her diagnosis in the past but the caregiver was uncertain if the individual remembered. For these 6 participants, the caregivers requested that the phrase *memory loss* or *memory impairment* be used during the research process rather than the word *dementia*.

At the initial meeting, the study was again explained. Each participant with AD was asked questions to ensure his or her understanding of the study. Consent was obtained from all participants. A release to reprint photographs was signed by all participants. The SPMSQ was administered to all persons with AD at the initial meeting. The first 4 participants with AD were given a twelve-exposure disposable camera for approximately one week and asked to take pictures representing situations that inhibit or support the experience of happiness. Each person with AD was accompanied by his or her caregiver to assist with logistical concerns. Two additional meeting dates and times were established—the first in seven to ten days to pick up the cameras for film development, and the final meeting was set approximately four days after film pickup for the interview. For all 4 participants with AD, the final interview occurred approximately

10 to 14 days after they received the camera.

The last 8 participants with AD were contacted and consented in the same fashion as the initial four individuals. However, the final 8 participants were accompanied by me rather than the caregiver when taking the pictures. This change in protocol was made to allow me to understand the participant's reason for the selection of the photograph and to note any change in rationale that might be given during the interview**.**

At the first meeting, a date and time was set to take pictures within three days. Pictures were taken by the individual with AD using either a disposable camera, my digital camera or the individual's own camera phone. The pictures were then downloaded onto my computer and printed out on a digital printer. The final meeting occurred within two to three days after taking the pictures. In this way, I met with each of the 12 participants with AD three times during the study—once to explain the study and obtain consent, a second time to either retrieve film for the first 4 participants or to take photographs with the final 8 participants, and the final time for the interview.

Caregivers took photographs independently using either a disposable camera or their camera phone. Caregivers were interviewed individually, separate from the care recipient interviews, approximately four days after picture taking. All 12 participants with AD and the 10 participating caregivers were instructed to take pictures representing happiness from the perspective of the person with AD. The photographs were then used as a catalyst for discussion at the final meeting.

Semistructured, open-ended questions were used in the interview. Each person with AD and caregiver was interviewed individually. The photographs taken by the interviewee were placed on a table one at a time, and each individual was invited to tell

me about each picture and explain the reason the picture represented happiness. Each picture was accompanied by the initial question: *In what way does this picture represent happiness to you (or for the person with AD)?* From that point on, the discussion of the picture and any subsequent questions were based on the participant's responses. All participants were able to take photos and answer questions.

Interviews were audio-taped and professionally transcribed by an outside source. At the conclusion of the interview, field notes documenting the my observations—including descriptions of the setting, nonverbal behavior of the participants, and my overall impressions—were written. Personal notes were kept in a reflexive journal. Photographs were numbered to correspond to the taped interview. Transcripts of the interviews were coded concurrently as subsequent interviews and data collection occurred according to grounded theory technique.

Data Analysis

This research is informed by the theoretical principles of symbolic interactionism, which asserts that the meaning human beings assign to events in their lives is derived from interactions with others and from their participation in a particular historical and cultural context (Blumer, 1969). Concepts from Kitwood's theory of personhood (1997) provided the lens through which I interpreted the utility and implications of the findings.

Interviews were digitally recorded and professionally transcribed. The transcripts were reviewed for accuracy and read several times to increase familiarity with the data. Interviews were transcribed, coded, and analyzed as completed, staying close to the data. In vivo codes were initially applied to the transcripts to preserve the participants wording of their ideas and meanings. In vivo codes were included in the comparative analysis

process. The next coding phase was line-by line coding which allowed me to identify concepts and processes, and to see the nuances within the data. These codes were subjected to the same comparative and analytic treatment as the in vivo coding. Using NVivo software to analyze the codes, categories were identified which came directly from the data. Focused codes were developed through application of the comparative process to the identified categories which led to the development of themes. Themes were identified and coded for each transcript. Once all individual transcripts had been coded, repeating patterns of similarities and differences were identified over all the transcripts and discussed with a colleague experienced in qualitative analysis who was familiar with the study and data. Memos that summarized relevant information for each participant were maintained throughout the research process. (Bradley, Curry & Devers, 2007).

Analysis of the coded concepts found in the care recipient data was conducted initially, leading to group themes common to the participants with AD. Data obtained by the caregivers was then analyzed as a group in a similar manner, leading to the identification of themes common to the caregivers. In this way, group themes were assessed to identify concepts or aspects of happiness for the person with AD as understood or experienced by each group as compared to the other. The final step involved pairing the care recipient data with that of the caregiver to compare the themes within the dyad, identifying similarities and differences within each dyad.

General Observations of the Study Participants

Caregivers were able to express their thoughts clearly. All reported increased stress levels since taking on the role of caregiver; 6 of them reported attending a support group, and 5 of them reported receiving treatment for depression or anxiety. One

caregiver was recently diagnosed with mild cognitive impairment, another with AD. Two spouse caregivers reported physical impairments that made caring for their spouse difficult and that resulted in the assistance of a home health aide one hour each day.

The participants with mild to moderate AD displayed varied cognitive and language abilities but all were able to communicate their thoughts with some limitation, mostly related to word retrieval skills. The presence of a comorbid affective disorder has been posited as one cause of the disparity between subjective and proxy reports of AD quality of life (Moyle et al., 2012). Of the 7 care recipients reportedly receiving treatment for affective disorders, only 1 reported feeling depressed at the time of the interview.

The first 4 participants diagnosed with AD had some difficulty remembering why they had taken a photo. These 4 participants with AD were accompanied by their caregiver during picture-taking; the final 8 were accompanied by me. This change occurred in response to the memory difficulties experienced by these 4 participants in an effort to shorten the time from picture taking to interview and to understand the rationale for photo selection. I believe this change may have allowed some participants to more easily remember their reason for photo selection. However, the photographs were not used as representation of objective truth but rather as a springboard for dialogue. Through discourse, the experience of happiness was cocreated by me and the participant, as occurs when pictures supplied by the researcher are used during the interview. I consider the findings drawn from the interviews with the first 4 participants with AD to be as valid as the findings drawn from the final 8. This belief was supported in follow-up interviews with 2 of the initial 4 participants in which my categories and interpretation of the data were confirmed as reflections of their ideas.

All activities conducted during this study were reviewed and approved by the Institutional Review Board of the University of Utah. The names and initials of all participants have been changed to safeguard confidentiality. Consent was obtained from all participants and a release to reprint photographs was signed by all participants.

Findings

Three categories emerged across caregiver data: interconnection, nature, and activities as a way to keep busy. Within each category, observed differences and commonalities between the information obtained from the caregivers and the participants with AD are discussed, as were the sources of happiness that were missed by the caregivers. Systematic analysis and coding of the transcripts suggest disparity in the subjective assessment of happiness between persons with AD and their caregivers along with factors contributing to the discordance. The findings presented here represent the experience of 20 individuals and are connected to their race, class, gender, and social situation; therefore, these findings may not be generalizable. However, the intention of this study is to report on the presence of happiness and well-being in AD from the perspective of the caregiver, comparing and analyzing the perspective of the care receiver to that of the caregiver proxy. This study is not intended to generate generalizations.

Connection to Others: Perception of Self

All caregivers believed connection to another person or animal was important to the care recipient's happiness. Animals were identified as a lifelong source of joy and entertainment. One caregiver understood the interest in a pet as a reflection of her role as nurturer to her children.

JP (son caregiver): She's always loved dogs. We had pets...We've had other stuff too but I know she always asks about Lexie (pet dog). She wants to give her a biscuit whenever she sees her. She asks about her paw that sometimes gives her problems. Like she used to ask us about the kids.

ES (son caregiver): The dog has become his best friend. (My parents) always used to have big dogs, but this little dog is his best buddy now.

Family was identified most frequently as the most important source of happiness. The interaction between the person with AD and family was described by the caregiver as a one-directional relationship, with the person with AD taking the role of an observer rather than an active participant. Research results reported earlier from this study (Shell, unpublished manuscript, 2013) found the participants diagnosed with AD identified family as the most important source of happiness. However, participants with AD generally used active terms to describe a bidirectional relationship, in which they played a larger role than suggested by the proxy, including nurturance and stewardship.

JP (child caregiver): Grandchildren, family. She always asks about how are they doing, what they're doing, working, school, college, whatever happened to them.

LP (person with AD): I do enjoy flowers, both the garden part and the flowers. I like working in the yard (more than) my daughter.

EM (wife caregiver of WM): If we were going to have say a Bar-b-q or something he (husband) liked setting up tables...He doesn't seem to have the incentive anymore that he used to have.

WM (person with AD): I have, my son, he lives in Pennsylvania and he's a mechanical engineer. . . . He helps me an awful lot. . . . And by the same token,

> when he moved (last month) from one place to (a second), I came down and helped him do whatever had to be done . . . it felt good being able to do things to help him out.

Results of the study reported elsewhere (Shell, unpublished manuscript, 2013) noted that 9 persons diagnosed with AD connected happiness with the deep connections to others and a sense of belonging. For most, the importance of connections and community were expressed in an historical context and as an element missing from their current living situation. The importance of community and giving back to others was acknowledged by only 3 caregivers. In one instance, the caregiver acknowledged but invalidated the participant with AD's longing for friends with whom to play bridge, which resulted from friends moving to a nearby senior center.

> SWH (daughter caregiver): I don't know if they're playing bridge. . . . She's not one, nor is Daddy one, to be "herded," herded onto a bus to go on a scenic tour whether it was a seniors' group or friends. I think the grass is greener on the other side kind of a thing. . . . Daddy and I feel it's very confusing for her to take up at this point and go to this elite place. One, because she's not good at spending money; two, it ultimately will be very confusing for her. This is where her stuff is and she couldn't take her stuff with her. Her stuff is important to her.
>
> DW (person with AD): Once people (friends) move in to those places, they connect and you're sort of left as the outsider, and after a while it's easier. Well, as I said, my bridge groups all broke up because people went to those places and you got invited for a while, but after a while it was easier for them to stay there than it was to come out.

Nature: Beauty and Spirituality

Nature—represented through pictures of birds, trees, plants, and the ocean—was reported by 7 caregivers as an essential source of happiness to their partner. For most caregivers, nature was understood as a visual experience, something their partner looked at and admired. One caregiver, TG, placed her care recipient in a historical context, reporting the beach as a spiritual place that connected her partner to earlier years and to her deceased husband. One daughter, SWH, identified nature as a way for her mother with AD to feel needed. In contrast, SWH's mother described gardening as both a joy and a way to lose any sense of responsibility.

In general, the meaning of nature was individualized and more active for the persons with AD, reflecting self-sufficiency, strength, peace, and freedom. Some identified nature as a source of peace and spiritual connection that served as a route to transcend the disease.

> SWH (daughter caregiver): I was on the other side weeding. She allowed me to weed because normally, a lot of times, she does not trust Daddy to do her job but she will trust me. I could have done this in—I just wanted to talk with her. But while I'm weeding . . . she feels needed. She thinks I can't do this.
>
> DW (person with AD): I've always liked to work outside and I don't consider it work; I consider it joy. . . . It's like you're outside and you've lost any sense of responsibility; you're just out there.

Activities as a Way to Keep Busy

Several activities were identified by both caregivers and persons with AD as sources of happiness, including sewing, music, golf, and bird watching. Looked at

together, individual differences were evident, and the caregiver's understanding of the importance of the subject frequently differed from that of his or her partner with AD. Activities were mostly reported by the caregiver as a *behavior* enjoyed by the individual with AD.

As reported in an earlier article (Shell, unpublished manuscript, 2013), the participants with AD frequently identified the same activities as the caregiver as those that were meaningful. However, the meanings shared by the care recipient went beyond the activity itself and were frequently connected to an important, long-held *value*.

> MA (spouse caregiver): He [enjoys golf] and plays when the weather is decent.
>
> AA (person with AD): I think what I'm seeing there [in the photograph] is —here I am [with the] guys. As you see, everything's going well and I'm having fun. . . . I don't want anybody saying "Oh, that's too bad" or "Isn't that a shame." I don't want that kind of thing. This is the way I think of myself.
>
> AL (spouse caregiver): Dory is a bird lover, birdwatcher, has been for years. She likes looking at birds.
>
> DL (person with AD): I love birds . . . they're beautiful, that may be a striker or something like that, but mostly beautiful I met some wonderful people. You're outdoors, most of the people are outgoing, and once you get to know one another, you're just part of the special group.

Missed Sources of Happiness

Within each dyad, some of the sources of happiness identified by the person with AD were not mentioned by the caregiver. The caregivers were notified of their omission; each reported it as an oversight, not the result of unawareness. Sources of happiness

missed by the proxy reporters included God, being active and busy as a reflection of health, thinking of the family's future, and the home which is viewed as a safe environment without physical impediment and fear of embarrassment about memory impairment. The omission on the part of the caregiver of these important sources of happiness may suggest a conceptual difference in how happiness is understood and assessed by persons with AD and caregivers, or it may be an inherent limitation of any proxy report in which reflexivity is not stressed.

The caregivers interpreted the task of taking pictures representative of happiness for the person with AD very concretely, considering objects and actions that are observable and to which indicators of enjoyment were clearly evident. In each case, the values that were not identified by the proxy caregiver were areas of great importance to the person with AD. In each case, the caregivers understood the represented value for its historical context, but expressed surprise that the care recipient retained the value. It seems reasonable to infer that this might occur at other times when asked to step in as proxy to represent the thoughts, concerns, and wishes of the person diagnosed with AD.

> L. Shell: There were pictures of shoes, sneakers, her great grandson's sneakers. She said, "I like thinking about what's happening in the future. I like thinking about where he's going. I like thinking about where my family's going even when I'm not here."
>
> JP (son caregiver): Wow! That's magnificent. I used to hear her talk about the present—I don't think about her talking about the future now.

Response of the Person with AD to the Diagnosis of AD

Coming to terms with a diagnosis and manifestations of Alzheimer's disease is a complex task for both the individual and those who care for him or her. The descriptions by the participants of their experience of *becoming* a person with AD or a caretaker underscore the profound loss of self and the ensuing effort expended to preserve self. I start with the intrapsychic response of the person with AD, the preservation of self.

Preservation of Self for Person with AD

Multiple losses occur in Alzheimer's disease that may upset self-image, including loss of independence, social isolation, cognitive changes that prevent completion of previously attainable goals, and memory impairment; together, these losses may lead to loss of self (Cotrell & Schulz, 1993). The loss of self experienced by the participants with AD may be influenced by the social context and possibly by their knowledge of being diagnosed with AD.

All participants with AD acknowledged memory loss as a personal challenge to self; many also described fear of making errors and worry about future loss. Some were able to retain a sense of self by considering change as part of aging, thus suggesting a social context that may allow preservation of the self while still acknowledging decline. For those who knew their diagnosis, AD played a role in their interpretation and expectations of the future.

> AA (person with AD): I'll be honest with you. . . . I don't plan on going out slow. I don't want to go that way and particularly putting—I don't know where in the hell I am or what's going on. If I'm making the people I love, putting them in cases where they have difficulty that they don't deserve.

Response of the Caregiver to the Partner's Diagnosis of Alzheimer's Disease

In addition to coming to terms with changes associated with their role as caregiver, the caregiver must also adjust and respond to the changes in his or her partner. In this section, I start with the intrapsychic response of the caregiver to the person with AD, followed by the preservation of self for the caregiver.

Response to the Partner's Diagnosis and Expression of Alzheimer's Disease

All caregivers reported an understanding of AD as an incurable and progressive neurologic disease associated with cognitive, physical, and behavioral changes. Still, all expressed a general sense of confusion, at times interpreting cognitive or behavioral changes as acts of volition and an expression of personality, and other times as the expression of AD. Thus, some caregivers questioned the motives of the individual with AD and expressed anger directed at the care recipient for what the caregiver believed to be manipulative behavior. Many caregivers spoke of not knowing when to accept the limitations of the person with AD as the "best they can do" or when to encourage their partner to do more. For many, this tension resulted in frustration and guilt.

In contrast, each person with AD articulated dissatisfaction with the cognitive changes he or she was experiencing, but no one expressed the belief that these intrapersonal changes were either voluntarily or a reflection of his or her personality. All 10 participants conveyed frustration with the cognitive and physical decline regardless of whether they were assumed to be organic and associated with aging or neurologic and associated with AD. All spoke about the challenge of trying to maintain independence and relationships while simultaneously accommodating memory deficits. Responses of the care recipient to memory changes varied, including normalizing, minimizing,

frustration, fighting to retain function, and humor. These strategies may be useful tools for adaptation to the effects of AD.

An additional challenge identified by the caregivers relates the need to balance the sometimes extensive monitoring, coordination, and hands-on delivery of medical services with the person with AD's desire for independence and control (Gitlin & Schulz, 2012). It is at these times that the care of the AD comes at the expense of the individual's personhood. This following example from one of the caregiver interviews highlights the interrelationship of the caregiver and the care recipient and the challenges of balancing medical needs with personhood.

> SWH (caregiver): She's on Synthroid 50 mg, Synthroid and that's been since she was 40. Aricept—no, no, let me just say she's supposed to be on Aricept. She does take her Synthroid. Must be on Aricept, supposed to be on Namenda, and then she's supposed to be on Zoloft, which she doesn't like to take. That will spark an argument. . . . We also use the vitamin boxes because . . . I'm big into holistic treatment. I said, "You can put the big omega three's in there, Mom." There are big enough boxes for that. That is her control thing; it gives her some control.

Preservation of Self for the Caregiver

The stress associated with caregiving and leading to the caregiver's burden has been well documented in the literature. Pearlin, Menaghan, Lieberman, and Mullan (1981) reported that certain life events and role strains can have deleterious effect on well-being through their adverse influence on self-esteem and mastery; they describe the impact of role strain on the self as "the diminishment of self." "Persistent role strains can

confront people with dogged evidence of their own failures—or lack of success—and with inescapable proof of their inability to alter the unwanted circumstances of their lives" (p. 340). I suggest that the observation by Pearlin et al. (1981) of the effect of role strain on sense of self may apply to those caring for a person with AD.

All caregivers described a narrowing of their life in the present as compared to the time before they became a caregiver. Caregiving daughters noted a decrease in time spent in their profession. The social contextual nature of AD for both members of the dyad was reflected in the change of social patterns. Time spent in social activities decreased, both because of the time taken up with caregiving responsibilities and also because the spouse with AD may choose to limit social engagement to avoid embarrassment or making a mistake. One caregiver wondered if friends were now avoiding the pair due to discomfort around the person with AD. One daughter expressed feeling engulfed by her caregiving and noncaregiving responsibilities and felt she was left with less time for enjoying life.

> SP (daughter caregiver): She was disoriented after we moved there, she couldn't function for weeks and I was working full time. . . . Now I work part time. It's horrible. . . . She doesn't talk to me much other than what's new, how was your day? I come in last night at seven, she's got food out all over the place. I'm trying to make dinner. . . . Cups of tea all over the place. [I spent time cleaning up] and an hour later, she had cake and tea and I had to clean up all over again.

One of the primary causes of loss of self is the way in which others treat the individual with Alzheimer's disease (Sabat & Harre, 1992). Caregivers frequently identified loss through a comparison of the person with AD's current self to his or her younger, healthier self. There was no indication of a belief that change may be related to

increased age or life experience. However, two caregivers noted a positive change in their relationship to the care recipient.

> ES (son caregiver): My father went from being a workaholic kind of guy, very driven and depressed when he was having problems with his work and his marriage. Now he's a contented, pleasant guy who enjoys being with his family and values his family very much.

One spouse reported that her marriage has improved since the diagnosis of AD.

> PC (spouse caregiver): I think he sees what I'm doing for him and I know that he would do the same for me where the table is turned. I have no doubt about that.

Discussion

In this study, the initial 4 participants with AD were accompanied by their caregiver during picture-taking; the final 8 were accompanied by me. This was done in response to the difficulty noted by the participants with AD in remembering their thoughts while taking some of the pictures. I believe this change may have allowed some participants to more easily remember their reason for photo selection. The photographs were not used as representation of objective truth but rather they functioned as a springboard for dialogue. Through discourse, the experience of happiness was cocreated by me and the participant, as occurs when pictures supplied by the researcher are used during the interview. I consider the findings drawn from the first 4 interviews to be as valid as the findings drawn from the final 8. This belief was supported in follow-up interviews with 2 of the initial 4 participants in which my categories and interpretations were confirmed as reflections of their ideas.

A review of the photographs taken independently by both members of the dyads

in this study revealed general concordance in subject matter, reflecting an overall shared understanding of the activities, people, and objects related to happiness for the individual with AD. However, while the photographs taken by both members of the dyad demonstrated considerable similarity in construction, the meaning ascribed to the photos were very different. One overriding factor contributing to discordance of the appraisal of happiness between care recipient and caregiver was the presence or omission of values, which I suggest is the result of perceived loss of personhood. Based on work in the fields of positive psychology (Park, Peterson & Seligman, 2004) and social psychology (Schwartz, 1994), I defined a value as a desirable goal that serves as a guiding principle in one's life; transcends specific situations; and guides one's assessment of behavior, events, others and ourselves. Findings of this study suggest intrapersonal processes of the caregiver and the care recipient, as well as interpersonal processes between the two, are involved in the evaluation of happiness in AD.

Values

Analysis of the findings from the study of happiness in persons with mild to moderate Alzheimer's disease has been reported elsewhere (Shell, unpublished manuscript, 2013). In summary, activities and experiences identified that represented happiness were ones that supported the personal values of the person with AD. Participants with AD used photographs to represent deeply held values central to the individual—values that were minimally impacted by cognition. The explanation of the photographs and rationale for its selection was nuanced, related to personal values and situated in a social or historical context.

In contrast, the caregivers frequently took similar photos of tangible objects or

activities of their partner with AD but then offered a superficial explanation for selection of the photo that reflected a limited understanding of the subject's importance to the care recipient. At other times, caregivers completely missed sources of happiness described as important by the person with AD that were exclusively value-ladened, including a belief in God.

One is left to wonder if the caregivers were aware that values continued to be important to their partner. It is possible that the caregiver lacked an understanding of what matters in life to the care recipient, or the subjective experience of "being" for the individual, a fact that may be unrelated to the presence or absence of AD. Values such as security and belonging are generally explored in dialogue. Verbiage is a common way that we connect personhood with cognition and convey the capacity to transmit linear cognition—something Western society highly values. Yet individuals have differing levels of personal insight and varying degrees of comfort in the expression of private, reflexive thoughts, so the lack of understanding may represent the ability or comfort of the caregiver to discuss these topics.

Another possible explanation is that the omission of values reflects a care recipient-caregiver relationship in which emphasis is placed on the pathological expression of disease rather than the development of an interdependent, mutually beneficial relationship that supports the personhood of both parties. From a social constructionist perspective, social phenomena such as identity and personhood are created through an interpersonal process that can be constructed only in interaction with another (Adams & Gardiner, 2005). Therefore, personhood for an individual can be created only if it is recognized and acknowledged by another person. Reducing the care

recipient to a set of signs and symptoms incapable of reflexive thought or insight constricts possible roles or personae a person may take on and jeopardizes the individual's personhood.

Using the framework of symbolic interactionism and social constructionism to understand the intra- and interpersonal nature of the care recipient-caregiver relationships, preservation of self is seen as the result of the interaction between both members of the dyad. In the interviews with the persons diagnosed with AD, each person talked about his or her frustration with cognitive and physical decline and the effort devoted to finding ways to compensate with these impairments. However, the findings of this study suggest that caregivers are conflicted in their view of their partner's limitations, at times seeing the person with AD in the adversarial or childlike position of one who is "choosing" to be contradictory, and other times as a patient doing "the best he can." As the result of either view, the caregiver's understanding of the person with AD is limited and does not fully recognize the individual as an adult, instead giving the individual a standing of child or patient with cognitive impairment. The social constructionist view would suggest that this constricted view of the person with AD may affect the care and the opportunities given to care recipient.

The symbolic interactionism and social constructionism frameworks are also useful in understanding the findings of this study, which suggest that the intersubjective space created by the caregiver-care recipient relationship not only affects the care recipient's sense of self but also affects the caregiver's sense of self. Caregivers reported sadness watching their spouse or parent experience dementia-related decline, frustration at not being able to stop the disease progression, and frustration at the limitations the role

of caregiving places on other areas of their life. For some, job- and family-related stress and unresolved interpersonal conflict with the dementia-diagnosed individual make caretaking more difficult. Thus, the intersubjective space created by the caregiving process may leave both the caregiver and the care recipient with constricted roles that affect how each is viewed by the other. This also supports Kitwood's (1997) concept of personhood, which highlights the social context of AD and affirms the importance of the interaction and communication between the caregiver and the person with AD in the expression and understanding of AD symptoms.

The perspective of social constructionism and symbolic interaction suggests we look at the impact of AD on the caregiver. A review of literature yields a multitude of articles suggesting ways to educate and train caregivers to take on new roles in the hope this will lessen caregiver burden (Parker, Mills, & Abbey, 2008). Ward-Griffin (2012) questions the effectiveness of this behaviorist approach, suggesting that a better understanding of the caregiver-provider relationship is needed to understand the hesitancy for caregivers to use available professional services. Given the stress expressed by the caregivers, I believe we need to find a way to support both the caregiver and care recipient, identifying interventions to help the caregivers feel better about what they are doing rather than just focus on the behavior of the person with AD.

Person- and family-centered care (PFCC) has gained attention in recent years, in response to the growing awareness of the strain placed upon family and partner caregivers. PFCC advocates delivery of services that support the older person and their family's goals, values and needs and integrates the family caregivers as partners in care delivery (Levine & Feinberg, 2013). Focusing on person- and family-centered care rather

than solely person-centered care may provide the best way to support the collective well-being of both the caregiver and the person with AD.

Future Studies

This research, like most qualitative research of the lived experience of AD, was conducted with a sample of individuals with mild to moderate disease and their caregivers. As a result, there is a limited understanding of the experience of those in the more advanced stages of illness.

Longitudinal prospective studies examining changes in the subjective experience of happiness and personhood in AD over time are needed to provide this information. Further study is needed to see what effect, if any, choosing value-supporting interventions will have on the quality of life and the expression of AD as well as the intrapersonal and intersubjective effect of incorporating value-laden activities on the carer-caregiver dyad. Further study is also needed to understand what effect personhood has in both the person with AD and the caregiver. This should include study of the impact of personhood on the caregiver as well as the care recipient.

Assessment tools that lead to a contextual and historical understanding of the individual with AD's values and beliefs are needed in light of the lack of knowledge or understanding of these attributes by the caregiver. Interventions are needed that support the values identified by the individual, rather than focusing solely on activity level and interests. Additionally, replication in communities throughout the United States and internationally are needed to confirm the role of values in AD. Finally, discrepancy between the assessment of happiness of caregivers and care recipients suggest that when possible, evaluation of positive emotion should be sought from the person with AD.

Study Limitations

The sample size of this study is small, limited to one state in the northeast United States. Findings may be connected to class, race, and social situation common to this area and may not be generalizable.

Conclusions

Through the recognition of subjective and intersubjective components of the caregiver-care recipient relationship, one can begin to construct a contextualized understanding of the lived experience of Alzheimer's disease for both the person with AD and the caregiver. Results from this study of subjective happiness in AD point to the existence and continuation of lifelong values at least into the mild and moderate stages of Alzheimer's disease that influence the happiness and therefore quality of life in AD-diagnosed individuals. However, study results point to a general lack of awareness and understanding of the presence and role of these values by the caregiver, possibly the result of a constricted view of the person with AD that excludes the possibility of insight or reflexive thought, thus a limitation of personhood.

Identification and appreciation of the values central to the person with AD is important on both a therapeutic and theoretical level. First, seeing the person with AD as an individual with values underscores the individual's personhood and continuation of the predisease self despite the presence of disease. Second, recognition of the individual's lifelong values may move the caregiver away from the immediacy of choosing activities as necessary diversion toward choices of therapeutic interventions that more authentically support happiness and quality of life. Taken together, the appreciation and incorporation of values may result not only in the choosing of activities that support the individual's

values but also the joining of the caregiver and care recipient in the intersubjective space—not just supplying the yarn and crochet hook to the individual to keep her busy, but crocheting together with a shared understanding of the importance of the work as a way to nurture one's family.

Finally, perhaps it is time to put to rest the discussion of which assessment of quality of life is "correct"—proxy or subjective report of the person with AD. I suggest we do not have to completely drop caregivers as proxy, but rather include both the perspective of the caregiver and the perspective of the person with AD in assessments. Supported by frameworks of social interaction, social constructionism, and Kitwood's theory of personhood, I suggest the truth may lie somewhere in between both perspectives, and both are needed to understand and develop interventions that support quality of life for those with Alzheimer's disease.

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CHAPTER 7

CONCLUSION

In this study, I explored the subjective experience of happiness for persons diagnosed with mild to moderate Alzheimer's disease (AD) by focusing on two research aims: (a) To describe the subjective understanding and perception of happiness in individuals with mild to moderate AD; and (b) compare what people with AD consider important to their happiness to what the caregivers believe is important for their happiness. Results of the study were divided among the three manuscripts presented in Chapters 4–6, focusing on the use of photo-elicitation methodology for this purpose, the findings among subjects with AD, and a comparative analysis of the reports of the subjects with AD and their family caregivers. A discussion of the major findings, summarized and compared across all three articles, is presented in this final chapter along with recommendations for future study.

Happiness from the Perspective of the Person with Alzheimer's Disease

The first major finding of this research is that people with mild to moderate AD can experience happiness, suggesting that an individual with AD can lead a meaningful life. The participants were all able to reflect on happiness in the present, past, and future tenses and to engage in a discussion of what happiness means to them in a fashion as sophisticated and nuanced as persons who are not experiencing cognitive decline.

Analysis of the transcripts revealed a connection between the continued

expression of, and engagement with, personal values and reports of well-being and happiness. Based on work in the fields of positive psychology (Park, Peterson & Seligman, 2004) and social psychology (Schwartz, 1994), I defined a value as a desirable goal that serves as a guiding principle in one's life; transcends specific situations; and guides one's assessment of behavior, events, others and ourselves. In this study, five cross-cutting values were identified by a majority of participants: nature, interconnection, transcendence, joyful moments, and preservation of self. The individual accounts within each value were unique, historically and contextually based, and constructed in relationship with other people. Therefore, values are not universal, nor are they strictly generalizable. The only way to obtain a contextualized understanding of happiness and other values is to spend time with the person and, through discourse and interaction, deconstruct the experience to better understand the contexts upon which it is based. Thus, this research suggests that current quality of life measures that purport to measure the complex concept of happiness on a simple scale are missing the intricacies and nuances of what really matters to the individual and thus are unable to adequately assess happiness.

In summary, values are not universal. However, findings from this study suggest that having values and living a life that supports those values and offers daily experiences that are aligned with these values, does seem to be universal to the experience of happiness.

Happiness for the Person with Alzheimer's Disease from the Perspective of the Caregiver

The second major finding of this research is that while photographs taken by both members of the dyad demonstrated considerable similarity in construction, the caregiver offered only a superficial explanation for the selection of the subject matter as a reflection of happiness. There was minimal mention of values, suggesting a limited understanding of the significance of the images to the care recipient. This may reflect a constricted view of the person with AD that excludes the presence of insight or reflexive thought.

Intersubjective Experience of Alzheimer's Disease

The third major finding of this study of subjective happiness in AD is the idea that personhood is an interpersonal process. Kitwood (1997) theorized personhood as both supported by and emanating from an interpersonal context that includes the caregivers. The person with AD can be seen as a person only if both members of the caregiver-care recipient dyad see the individual as a person. Thus, personhood is really a relationship and, as such, it is important to look at happiness from the perspective of both members of the dyad. Unlike traditional, more conventional orientations, Kitwood and symbolic interactionism provide a framework that can account for the complexity of daily interactions that contribute to personhood and give a perspective to understand and appreciate the disparity between personal and proxy subjective reports of quality of life.

Limitations

The sample size of this study is small, limited to one state in the northeastern United States, and may not be generalizable to other areas. However, the use of a small sample allowed for an in depth look at happiness in the context of Alzheimer's disease

and resulted in a more nuanced understanding of the experience than would have been possible in a larger study. The study data and analysis, and therefore the findings, are connected to class, race, and social situation and the specific findings may not be generalizable, though the principles of positive psychology, personhood and symbolic interactionism are generalizable. Lastly, the sample was recruited from referrals by outpatient geriatricians and may not reflect all persons with mild to moderate AD. Results may differ among people with more severe forms of AD. It is also unclear if the social interaction required to participate in photo-elicitation would be a limiting factor. Therefore, people with more severe forms of AD or those with little chance to practice social interaction may not do as well as the community-dwelling participants in this study.

Recommendations

Based on the research findings of this study, I offer recommendations for clinical practice, curriculum development, national policy, and research.

Recommendations for Clinical Practice

At the most basic level, clinicians must stop and consider their own assumptions about their clients with AD. Do we believe that the person with AD has been reduced to a child, unable to know or express his or her own preferences and needs? Is the person with AD viewed as an individual who is a *fighter* or someone *waiting to die?* Our own attitudes influence both how we interact with the individual and how we interpret behaviors. Yet the value of reflexive thinking is not supported in many settings where providers and caregivers are focused on meeting the biomedical needs of clients in a cost-effective manner. Without reflexive thought and insight, we risk providing care that may

sacrifice personhood to meet biomedical needs. Reflexivity must be part of every clinician's practice, supported by healthcare institutions through the provision of time, training for personal reflection, and opportunity for insight-oriented therapy.

Next, this research suggests that differences exist not just between those with and without AD, but also within each group. Values, identified as important to happiness and therefore quality of life, are not universal in those with AD. But though they are not universal in the sense of specific values, having them and experiencing happiness in relation to daily experiences that are aligned with these values does seem to be universal. This is a crucial point. While everyone may feel happier and more at ease when he or she is living life in accordance with his or her own deeply held values, what those values are for each person can be understood only by spending time with him or her to understand and draw the values out. Clinicians must spend time in constructive discourse and interaction in order to gain a contextualized understanding of values and happiness for each individual.

One example of a way get at values, similar to the photo-elicitation methodology used in this study, is through TimeSlips, a storytelling intervention program developed to give people with AD a way to communicate that does not rely on cognition or ability to access memories (Fritch et al., 2009). The person with AD is shown a picture and invited to make up a story about the image. Though not extensively tested, early research suggests involvement in the TimeSlips program is associated with increased engagement and positive affect of persons with AD and allows for a connection to occur between the caregiver and care recipient (Fritch et al., 2009).

In a fashion similar to TimeSlips, I believe pictures can be used to encourage dialogue between providers and individuals with AD aimed at the identification of

values. I suggest providers choose pictures that represent the values identified in this study: nature, family, transcendence, interconnection, and belonging, as well as pictures of individuals engaged in various activities to serve as a catalyst for discussion with individuals diagnosed with AD, with a goal of eliciting the individual's values. The pictures should be large enough for easy visibility, and light enough to allow the person to hold and thus connect with the image physically. Discourse centered on images selected by the individual as meaningful may provide a way for clinicians to access the individual's values through expressive coconstructed storytelling and careful listening. Once values are identified, interventions supporting core values, adjusted to the capability of the individual, may be used to maintain personhood and support a meaningful life, including the presence of happiness.

This research supports what has been discussed in depth in the literature: The work of the caregiver is extensive, multifaceted, and can lead to burden and exhaustion. While a significant focus has been paid to person-centered care, I suggest we direct our efforts toward a model that recognizes the needs of the person with AD and the caregiver. I suggest a multicomponent approach will be needed to maintain the emotional and physical health of both the caregiver and care receiver. Person- and family-centered care (PFCC) has gained attention in recent years as a way to address the strain placed upon family and partner caregivers. PFCC supports delivery of services that shore up the older person and their family's goals, values and needs and integrates the family caregivers as partners in care delivery (Levine & Feinberg, 2013). Key elements of the PFCC include: dignity for the older person and family; acknowledgement of the whole person; meeting the needs of both the person and the family caregivers; communication and shared decision making; emphasis on coordination and collaboration (Feinberg, 2012). In this

way, the individual with AD is able to voice their preferences and concerns, and both the person with AD and the caregiver are recognized as individuals and offered support. Shifting from patient-centered care to person-and family-centered care recognizes and supports the interrelationship between the person with AD and others in the social environment, including the caregiver.

Recommendations for Educational Curriculum Development

The findings of this study have implications for the education of all clinicians and researchers. The interviews point to the intricacies and complexities of people's lives and underscore the point that existential issues, including the experience of core personal and social values, are common for all humans. Educational curriculums must develop strategies to help students feel more comfortable discussing the existential issues with which all people struggle. These strategies cannot be limited to the undergraduate mental health class, but must be infused throughout the curricula to reflect the presence of these concerns across the healthcare spectrum. Students must be taught to identify and respond to the existential concerns of all patients, while simultaneously exploring their own emotions, thoughts, and reactions with peers and professors.

Recommendations for National Policy

We are on the brink of an Alzheimer's disease care epidemic. Public fear of the disease is evidenced in the multitude of articles in magazines suggesting ways to reduce personal risk. While the search continues for conclusive scientific evidence of interventions to reduce risk of Alzheimer's disease, some health factors and behaviors have been shown to increase the risk of AD, such as depression, smoking, and high body

mass index (Defina et al., 2013). I recommend we begin a national campaign to educate the public on brain health, using public service announcements to share information on risk-reduction strategies such as controlling cardiovascular risk factors, managing diet and physical exercise, and reducing the risk of head trauma.

Given the expanding role of the caregiver in the healthcare delivery system, plans should be developed to integrate caregivers into a person-and family-centered model of care. Population-based interventions are needed to prepare, educate, and support current and potential caregivers. Family caregivers are generally unpaid, yet their contribution to the economic burden is large. It is unclear if the cost savings for the person with AD outweigh the potential cost to the caregiver that may be incurred as a result of the stress of caregiving. A broad public health initiative is needed to study and address the issues facing caregivers.

The research findings presented in this study highlight the need to appreciate the uniqueness of the person with AD, including the historical and contextual nature of their values so as to develop interventions aimed to improve quality of life and support personhood. To fully understand a person's values requires a greater expenditure of time on the part of care providers and possibly extra training, and may therefore be more costly to provide. Medicare Fee-for-Service currently provides low reimbursement for services like counseling, yet this service currently may offer the best chance to improve the quality of life for many elders. The Medicare reimbursement system must be revised to compensate clinicians and care providers for their valuable services that support good mental health and quality of life.

Recommendations for Future Research

This research, like most qualitative research of the lived experience of AD, was conducted with a small sample of individuals with mild to moderate disease. Replication in communities throughout the United States and internationally and across ethnic, cultural, and economic groups is needed to confirm the role of values in promoting a subjective sense of wellness within illness for people with AD and their caregivers. Longitudinal studies examining changes in the subjective experience of happiness and personhood over time are needed to understand the experience of those in the more advanced stages of illness.

In addition, future studies of what influences caregiver perception formation, as well as ways to make caregiver perception more congruent to the care recipient, are needed. These studies would serve as the first step toward the development of interventions affecting the relationship.

Assessment tools that lead to a contextual understanding of the individual's values and beliefs are needed and must incorporate input from caregivers, family, and the person with AD. Assessment of the caregiver-care recipient dyad is required to ensure that needs are addressed and support is provided to both. Interventions are necessary that support the values identified by the individual. Further study is needed to see what effect, if any, choosing value-supportive interventions will have on the quality of life, the expression of AD, and the intersubjective experience of the caregiver-care recipient dyad.

Finally, this study suggests that caregivers are unaware of or may misunderstand or misinterpret the importance of values to the person with AD. These findings are minimally useful if they do not reach the people who are most able to enact changes and improve quality of life for the person with AD. Therefore, researchers need to make

efforts to ensure their findings are presented to caregivers and family members. It is my intention to publish the findings of this study on a website and a journal readily accessible to caregivers in addition to professional journals.

Final Thoughts

Wellness within illness suggests a life in constant motion, vacillating between health and illness, an existential state acknowledging the existence of both simultaneously. This is not a new concept. We have come to understand many chronic and terminal illnesses in this way, recognizing and appreciating an individual's strengths while acknowledging the medical symptoms of their disease. I suggest it is time we applied this same approach to Alzheimer's disease.

AD is a medical disease that straddles the line separating physical and psychiatric illness, and it carries the stigma of mental illness. Stigma presents a significant challenge to well-being and quality of life. An approach that looks for individual strengths in addition to acknowledging dementia-related symptoms may help to dispel the stigma surrounding Alzheimer's disease. Therefore, finding and acknowledging the wellness within illness in Alzheimer's disease and other dementias should be a therapeutic goal for medical providers.

Healthcare providers must encourage individuals with AD to remain socially and physically active, participate in meaningful activities, and strive to attain a quality of life of their choosing—the same counsel we give to individuals with other chronic and terminal illnesses. But words are not enough. We need to provide patients with the personal and community resources to make wellness within illness a reality for people with AD. Including the potential for wellness in our current picture of AD is a big task,

but one that may help create a more holistic understanding of AD—an understanding that challenges stigma and changes expectations from a life filled with loss to one of individuals and families that thrive and accommodate their illness while striving for optimal health.

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APPENDIX

COMPARISON OF BIOMEDICAL, KITWOOD'S THEORY OF PERSONHOOD, AND POSITIVE PSYCHOLOGY

	Biomedical Model	Positive Psychology	Personhood
Assumptions	Underlying assumptions of the biomedical model: • All illnesses stem from an underlying abnormality within the body (disease). • All diseases give rise to symptoms during the illness. • The patient is a victim of the illness. • The patient is a passive recipient of treatment, expected to cooperate (Wade, 2004).	Underlying assumptions of positive psychology: • Virtues such as human goodness and excellence are as important as disease, disorder, and distress (Peterson, 2006). • Positive states and traits are not necessarily the opposite of a negative state or trait (Duckworth et al., 2005). • Well-being will be accompanied by optimal functioning of multiple physio- logical systems (Ryff et al., 2004). • Subjective well-being is an essential to health (Ryff et al., 2004).	Underlying assumptions of personhood: • All human beings have five fundamental needs: comfort, attachment, inclusion, occupation, and identity (Kitwood 1997: 81). • A person with AD can experience well-being if his needs are met (Baldwin & Capstik, 2007, p. 92). • All losses and difficulties in later life, including AD, are socially constructed. • A "core self" remains no matter how severe the losses associated with AD (Baldwin & Capstik, 2007, p. 89).

	Biomedical Model	Positive Psychology	Personhood
Understanding of health	Health is the absence of illness.	Health is the combination of excellent status on biological, subjective, and functional measures (Seligman, 2008, p. 3). The core hypothesis of positive health is that the experience of well-being will be accompanied by optimal physiological functioning, which may prevent disease or promote rapid recovery (Ryff et al., 2004).	Health is competence in the practicalities of living; occupying several roles with success; intact interpersonal relationships; ability to work through an accept age-related losses; having needs met; being supported by social processes that encourage personhood (Kitwood, 1990).
Understanding of illness	Illness is described in terms of pathology, resulting from cellular abnormalities—a biological explanation of symptoms (Wade, 2004).	Positive psychology acknowledges the biological basis of illness, adds positive traits as an additional component; it is a supplement to the medical model (Seligman & Steen, 2005).	Illness is the result of both biological and societal factors, arising largely from unmet needs. Excess disability may result from care-giving situations that encourage dependence (Kitwood, 1997).
Happiness/Well-being	Not addressed	Authentic happiness includes: • The pleasant life, which involves fleeting positive moods and immediate experiences of pleasure. • The good life, arising from use of talents and	Happiness is the expression of inner peace and acceptance of cognitive losses (Baldwin & Capstick, 2007, p. 94).

	Biomedical Model	Positive Psychology	Personhood
		virtues and characterized by engagement. • The meaningful life, which is dedication to something larger than oneself. (Seligman, 2002).	
Role of the "other" in illness	Does not recognize psychological and social factors.	The "other" does not have a role in illness and is very individualistic.	The "other" has a role in illness development and as a therapeutic tool.

AD = Alzheimer's disease

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